The role of illness perceptions on outcomes in psychosis and bipolar

Stock, Jennifer

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Systematic Literature Review and Empirical Research Project

Jennifer Jane de Carteret Stock

Institute of Psychiatry, Psychology and Neuroscience

King's College London

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Supervised by

Dr Suzanne Jolley

Dr Rebecca Kelly

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Abstract

Introduction

Psychosis and bipolar are associated with significant negative impacts for individuals. Psychological and psychosocial interventions are recommended treatments, however engagement in mixed and there is limited understanding about mechanisms of effectiveness and predictors of outcomes. Illness perceptions have been extensively studied in a physical health context and found to be predictive of treatment engagement and outcomes. Evidence suggests that illness perceptions in psychosis and bipolar may show the same relationships, and thus form a potentially important treatment target. It is therefore important to better understand these complex relationships.

Aim

To examine the relationships between illness perceptions and outcomes in psychosis and bipolar, including the direction of these relationships. Outcomes of interest included distress, wellbeing, quality of life, functioning, positive psychosis symptoms, engagement, and change over time in illness perceptions.

Method

A comprehensive literature search of MEDLINE, EMBASE, and PsycINFO databases, returned 2573 references for screening. Inclusion and exclusion criteria were used to screen titles and abstracts, followed by full texts. References lists of included papers were also scanned resulting in a total of 33 included studies from 32 papers. Data extracted included details of participants, study design, illness perception and outcomes measures, and findings. A narrative synthesis was completed.

Results

Included studies varied in design, measurement of illness perceptions and outcomes, methodological quality, and inconsistency in findings which limits the specificity of conclusions. However, overall the studies demonstrated that more positive or adaptive illness perceptions were associated with better outcomes, including psychological distress, wellbeing, quality of life, functioning, positive symptoms, and engagement in CBTp or psychoeducation interventions. However, as these findings were largely from cross-sectional analyses, causal inferences are limited to findings from only a few longitudinal studies demonstrating variation in stability of illness perceptions over time without specific interventions and that perceptions of control and loss could improve during CBT and psychoeducation interventions.

Conclusion

Further intervention studies are needed to provide more evidence on the potential for changeability of illness perceptions and importantly to understand whether, and, if so, how, in the psychological treatment of psychosis and bipolar, change in illness perceptions is related to outcomes.

INTRODUCTION

Psychosis and bipolar are severe mental illnesses (SMI) characterised by overlapping clusters of symptoms. Psychosis is associated with positive symptoms i.e. hallucinations and delusions, disorganised, and negative symptoms i.e. amotivation and diminished expression. It is also often accompanied by emotional conditions, such as depression and anxiety (Hartley, Barrowclough, & Haddock, 2013). Bipolar is associated with extremes of mood including episodes of depression and mania or hypomania. It is also often accompanied by anxiety disorders (Cosoff & Hafner, 1998). Although psychosis spectrum disorders are distinct in diagnosis from bipolar, they frequently overlap in symptoms. For instance, paranoia can present in bipolar and affective components can be present in psychosis i.e. in schizoaffective disorder. Thus, research suggests the two disorders may lie on the same continuum (Rosen et al., 2012) and they are frequently treated within the same services.

Psychosis and bipolar are associated with significant negative impacts for individuals, including increased levels of disability (Rössler, Salize, van Os, & Riecher-Rössler, 2005), a higher risk of physical health problems (Chang et al., 2011), decreased life expectancy by 10 years (Rössler et al., 2005) and a suicide risk twelve times higher than in the general population (Dutta et al., 2010). There is also significant impact and stress for families and carers (Saunders, 2003). Evidence suggests that medication as treatment is only partially effective with up to 40% of those treated continuing to experience moderate positive symptoms, two-thirds continuing to experience negative symptoms and over a third continuing to experience affective symptoms; medication is also associated with side effects and additional health risks (NICE, 2014a).

Psychological and psychosocial interventions are recommended treatments for psychosis and bipolar (NICE, 2014a, 2014b). Cognitive Behavioural Therapy for psychosis (CBTp) has been adapted from CBT for anxiety and affective conditions and draws upon cognitive models of psychotic symptoms (Johns et al., 2019). Therapy is tailored to personal goals and the overall aim is to help through normalising, making sense of experiences, reducing associated distress and impact on functioning. CBT principles and techniques involve establishing links between thoughts, feelings and behaviours, re-evaluating appraisals, building on coping skills, and relapse prevention. Evidence from service data and clinical trials has demonstrated beneficial effects of CBTp on positive symptoms, distress and functioning compared to routine care (NICE, 2014a). However, engagement in CBTp varies. For instance, when offered it is often refused (Prytys, Garety, Jolley, Onwumere, & Craig, 2011) or only partially taken up (Garety et al., 2008).

Single case studies have suggested that the earlier stages of CBTp, which involve assessment and individual formulation and building a therapeutic relationship, do not lead to improvements in delusions and associated distress (Chadwick, Williams, & Mackenzie, 2003). Findings from the Psychological Prevention of Relapse in Psychosis (PRP) trial showed that engagement in full therapy, which included actively engaging in specific cognitive and behavioural strategies and interventions, moderated the effectiveness of CBTp for improving psychotic symptoms and levels of distress (Dunn et al., 2012). Partial therapy, which included assessment and active attempts to engage in therapeutic techniques, was not effective for improving symptoms and distress. Therefore, it is important to understand what factors predict engagement in therapy, how they interact with outcomes, and whether they can be targeted and modified through intervention.

A range of social cognition models has been used to understand individual responses to illness in a physical health context. The self-regulation model (SRM) has been the most commonly studied (Leventhal, Nerenz, & Steele, 1984), it has also been referred to as the common sense model (Leventhal, Meyer, & Nerez, 1980). It proposes that individual perceptions of illness are based on key dimensions and these determine individual coping responses and health related behaviours (Weinman, Petrie, Moss-Morris, & Horne, 1996). These dimensions include: beliefs about a specific illness in relation to its identity (what symptoms are attributed to it); cause (what is likely to have caused it); timeline (how long it is expected to last); consequences (impact on physical, social and psychological functioning); and cure and controllability (whether anything can be done to improve the condition and whether treatment could be effective). Individuals' perceptions of illness have been extensively studied in the context of physical health conditions and shown to impact on a variety of outcomes including psychological wellbeing and distress, social functioning and physical health (Hagger & Orbell, 2003). Additionally, illness perceptions are associated with higher adherence to treatment, better self-management and physical health outcomes (Broadbent et al., 2015; Charles, Ninot, & Sultan, 2011; Clarke, Yates, Smith, & Chilcot, 2016; Murphy et al., 2020; Ross, Walker, & MacLeod, 2004).

A previous narrative review discussing illness perceptions in severe mental illness suggested that in attempting to understand the relationship with treatment engagement and outcomes, it would be beneficial to draw upon the evidence already established in physical health (Lobban, Barrowclough, & Jones, 2003). Their review reported that studies investigating illness perceptions in severe mental illness have varied in terms of specific beliefs assessed and in relation to theoretical frameworks. An important distinction was noted between illness perceptions, which relate to the problem/condition (e.g. of experiencing psychosis) in general (secondary appraisals) as opposed to individual appraisals of specific symptoms e.g. hallucinations (primary appraisals).

The relationship between illness perceptions and insight has been considered in psychosis research. When illness perceptions have been assessed in physical health, individuals would be required to recognise having

a specific illness for them to have beliefs about it. However, when illness perceptions are assessed in psychosis, measures have been adapted to ask participants to consider their "problems" or "difficulties" and do not refer to a specific "illness" (Marcus et al., 2014). This allows flexibility in assessing illness beliefs in psychosis and bipolar, regardless of level of insight as it does not rely on recognition of illness or attribution to internal or medical causes. Previous research suggests that illness perceptions and insight are related but distinct concepts. For instance, one study found that illness perceptions, assessed by the Personal Beliefs about Illness Questionnaire (Broadbent et al., 2006) correlated with levels of depression and hopelessness but not with insight (Acosta, Aguilar, Cejas, & Gracia, 2013), assessed by the Scale for the Unawareness of Mental Disorder (Amador et al., 1993). Another study found correlations between only the cure-control subscale of illness perceptions and insight (Watson et al., 2006). It was suggested that the role of insight may depend on psychological mediators and that personal illness beliefs could change independent of level of awareness (Acosta et al., 2013). Therefore, it appears that illness perceptions relate to aspects of personal meaning which are associated with affect and distinct from measure of insight. This highlights the importance of assessing illness perceptions when investigating outcomes in severe mental illness.

Lobban et al. (2003) recognised two important areas of work in severe mental illness which do not fit within the SRM framework, namely investigating the impact of perceptions of social rank and beliefs about specific treatments, for example, their advantages and disadvantages, rather than beliefs about whether the illness amenable to treatment (which is included in the SRM). The review concluded that there had been a lack of testing of proposed causal links between illness perceptions and outcomes as most studies assessed associations from cross-sectional data. They suggested that CBT could be more extensively used to modify illness perceptions to directly demonstrate their potential causal role on outcomes.

A more recent systematic review which included studies of illness perceptions based on the SRM across all severe mental health conditions, found only four studies which focused on psychosis and one study on bipolar (Baines & Wittkowski, 2013). They reported strong cross-sectional relationships of high identity (many perceived symptoms), chronic timeline, and many perceived negative consequences with higher levels of anxiety and depression, and lower self-esteem, which have been linked to symptom maintenance and recurrence in psychosis (Lobban, Barrowclough, & Jones, 2004; Watson et al., 2006). Additionally, perceptions that psychosis causes negative consequences were most strongly associated with poorer quality of life, satisfaction with mental health and global functioning outcomes (Lobban et al., 2004). Another included study found that a belief that treatment would be helpful was associated with higher self-rated engagement with mental health services (Williams & Steer, 2011). Since this review, illness perceptions in psychosis have been linked with CBTp outcomes. For instance, a study using a brief CBT intervention to target persecutory ideation found that a low sense of control over mental health problems, negative perceptions about the helpfulness of therapy and that belief that changing thoughts, behaviour and perspectives is unlikely to be helpful, predicted worse outcomes in relation to

paranoia (Marcus et al., 2014). It was suggested that the extent to which the cognitive behavioural approach fits with patients' own ideas will impact on engagement and thereby on the effectiveness of therapy. Another study found that illness perceptions at baseline relating to cause, timeline and control predicted engagement in therapy, irrespective of symptom severity (Freeman et al., 2013).

Evidence suggests that illness perceptions in psychosis and bipolar play a role in understanding individual emotional and behavioural responses. It is important to understand this relationship further due to the impact of engagement in treatment and outcomes. An updated review of illness perceptions in psychosis and bipolar is needed. Particularly important is the inclusion of clinical trials of recommended psychological and psychosocial interventions to further understand potential mechanisms between illness perceptions, engagement and outcomes.

Aims

This review aimed to examine the relationships between illness perceptions and outcomes in psychosis and bipolar. This included seeking to understand the direction of these relationships, for which illness perceptions could be the independent or dependent variable, mediator, moderator, correlate etc. This review also aimed to explore whether illness perceptions are amenable to change, for example, during psychological and psychosocial interventions or whether they can predict the effectiveness of interventions.

Review questions

1. What are the relationships between illness perceptions and outcomes in psychosis and bipolar?
2. What are the directions of these relationships?

Outcomes/correlates of interest included:

- Psychological distress (e.g. anxiety and depression)
- Quality of life and wellbeing
- Severity of positive symptoms i.e. hallucinations and delusions
- Functioning

Specific outcomes of interest in relation to psychological interventions included:

- Change over time in illness perceptions
- Change over time in outcomes
- Engagement in psychological or psychosocial interventions e.g. attendance and adherence in CBTp or psychoeducation

METHOD

This systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009). The review protocol was registered on PROSPERO (registration number: CRD42018094471).

Search Strategy

A comprehensive systematic search of the literature was conducted to identify relevant studies on 13th August 2018 (appendix A). The search was repeated on 4th March 2020 to capture studies published since the initial search. This resulted in an additional 339 records, which were screened but did not identify any new studies eligible for inclusion. As recommended by the Cochrane Collaboration, electronic databases were searched in addition to scanning reference lists of included papers. The following databases were searched using OVID: MEDLINE, EMBASE and PsycINFO. MEDLINE and EMBASE were selected to cover the broad sweep of medical and health care. PsycINFO was included as it is a specific database for psychology and mental health. The Cochrane library was also searched.

Preliminary searches retrieved a limited number of papers, therefore the search terms were expanded based on exploration of different terms used interchangeably in the literature which are related to illness perceptions. Expanded search terms included the models on which illness perceptions are based or related to, for example, 'common sense' and 'self-regulation'. Expanded search terms also included other secondary appraisals which could relate to perceptions of illness, for example, internalised stigma and self-concept. However, these constructs are distinct from the definition of illness perceptions described in the literature and therefore papers were not included unless they explicitly assessed an illness perception dimension. Due to the broad research questions, there was no restriction on study design or analysis to ensure that the search strategy would return the maximum number of studies that had examined illness perceptions in those with psychosis or bipolar.

MESH terms and subject headings were considered, but not used as they retrieved the same number of papers in preliminary searches compared to the specified psychosis spectrum search terms. Searches were limited to papers published in English and since 1980 as this was when Leventhal, Meyer and Nerenz (1980) first presented the Common Sense Model (CSM) in publication upon which the concept of illness perceptions is based.

The following terms were searched in title and abstract fields:

Illness perception terms	(belief or attitude) adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking) OR (illness adj3 (perception* or identity* or representation* or self-perception* or attitude* or cogniti* or schema*))
	OR
Other terms/concepts related to illness perceptions	"common sense model*" or "self-regulat* model" or "perceived control" or "personal model*" or self-stigma or "explanatory model*" or (caus* adj3 explanation*) or "internali*ed stigma" or self-label or self-concept or "patient* perception*" or
	OR
Illness perception questionnaire terms	(IPQ or "illness perception* questionnaire" or BIPQ or brief-IPQ or IPQ-B or IPR-R or "revised illness perception questionnaire"))
	AND
Psychosis spectrum terms	(psychosis or psychotic or schizophren* or bipolar or bi-polar or unusual experiences or mania or hallucinations or delusion* or paranoi* or ARMS or "at risk mental state" or "ultra high risk" or (voice* adj3 hearing) or ((CBT or "cognitive behavio* therapy") and (voices or delusions)))

*Adj3 = adjacent within 3 words, * = truncation/wild card*

Study selection

Endnote X9 (2013) was used to screen titles, abstracts and full-text papers and to record inclusion and exclusion decisions.

Stage 1: Titles and abstracts were initially screened using the following inclusion criteria:

1. Include participants who have experienced, or been identified as being at risk of developing, psychosis or bipolar
2. Include a measure of illness perceptions in relation to psychosis or bipolar
3. Peer reviewed i.e. not books, book chapters, conference proceedings
4. Empirical study i.e. not a review or meta-analysis

Stage 2: Full text papers were accessed and screened using the following criteria:

Inclusion Criteria

1. Measures more than one dimension of illness perception in relation to psychosis or bipolar e.g. perceptions of cause and control
2. Measures an outcome of interest:
    a. Psychological distress e.g. anxiety, depression
    b. Quality of life or wellbeing measure
    c. Functioning
    d. Positive symptoms
    e. Engagement in psychological or psychosocial interventions
    f. Change in illness perceptions over time
3. Investigated the relationship between illness perceptions at least one outcome of interest
4. Published in English
5. Published 1980 onwards

Exclusion Criteria

1. Participants did not experience psychosis or bipolar
2. Only assessed negative symptoms of psychosis
3. Considered illness perceptions not directly related to psychosis or bipolar e.g. illness perceptions of physical health
4. Only measured one aspect of illness perceptions e.g. causal explanations, thus not allowing comparison of relationships between different dimensions of illness perceptions
5. Explored illness perceptions from the perspectives of other i.e. health professionals, families, general population
6. Illness perceptions were assessed in relation to only one positive symptom e.g. hearing voices rather than a mental health condition
7. Considered adherence only in relation to medication or other non-psychological interventions
8. Engagement was assessed only in relation to mental health services in general, rather than engagement in a specific psychological intervention
9. Not able to extract data on the relationship between illness perceptions and outcome of interest
10. Not peer-reviewed e.g. book chapters, conference proceedings, Masters' thesis
11. Not an empirical study e.g. literature review

Reliability of screening

To ensure inter-rater reliability of the screening process, ten full-text papers were randomly selected and screened for inclusion by another reviewer. There was 100% agreement in papers selected for inclusion between the two reviewers.

Quality Assessment

The methodological quality of each included study was assessed using the Quality Assessment Tool for Quantitative Studies (QATQ) (Thomas, Ciliska, Dobbins, & Micucci, 2004); see appendices B and C for further detail). This tool was developed as part of the Effective Public Health Practice Project (EPHPP) to assess quality and risk of bias at different stages of the research process. The overall rating is derived from six component ratings: selection bias, study design, confounders, blinding, data collection method, withdrawals and dropouts. The companion document (Dictionary for the EPHPP QATQS) was used to assist in scoring each component as 'strong', 'moderate' or 'weak'. A paper was then rated as 'strong' overall if there were no 'weak' component ratings, as 'moderate' if there was only one 'weak' component rating and as 'weak' if there were two or more 'weak' component ratings. This tool was selected due to the flexibility of its' use with different study designs. The Cochrane handbook recommends subjectively identifying dimensions which are most relevant for specific reviews i.e. whether lack of blinding might have plausibly affected occurrence of a serious condition (Higgins et al., 2019). Therefore, components deemed to be not relevant to this review were not rated i.e. blinding.

To ensure inter-rater reliability of quality assessment, all included papers were rated by another reviewer. Discrepancies in component ratings were discussed and resolved (4% of questions within component ratings). This resulted in a change in 1% of component ratings but there were no differences between reviewers in overall ratings for papers.

Data Synthesis

A narrative synthesis of eligible papers was conducted due to the wide range of study designs included in this exploratory review. There was not a reasonable number of included quantitative studies that were sufficiently homogenous for a quantitative synthesis to be carried out. Data extraction of study findings were grouped in separate tables according to study design: cross sectional analyses, longitudinal analyses and intervention studies. Studies that included more than one type of analysis e.g. cross-sectional analysis at baseline within a longitudinal study, were reported separately within the appropriate tables. Findings within tables were then separated in columns for each illness perception dimension by outcome of interest. Findings were then qualitatively synthesised for each outcome of interest.

RESULTS

Study Selection

The CONSORT diagram illustrates the results of study selection (Figure 1.1). The search identified a total of 4743 papers to be screened. Duplicates were removed using OVID (n = 2109) and manually in EndNote (n = 61), which left 2573 papers to be screened. The Stage 1 screening process resulted in 193 full text papers to be assessed for eligibility at Stage 2. This resulted in 26 papers eligible for inclusion. Scanning of reference lists of included papers identified an additional 22 full-text papers to be assessed for eligibility, which resulted in an additional six papers for inclusion. The reasons for exclusion at Stage 2 are included in the CONSORT diagram. The repeated search resulted in an additional 339 titles and abstracts to be screened, however none met criteria for full text screening.

Study Characteristics

Characteristics of each study are shown in Table 1.1. One paper included three studies within it, of which Study 1 and Study 3 were eligible for inclusion (Birchwood et al., 2005) resulting in a total of 33 studies included in this review. Within the 33 included studies, there appeared to be 27 unique datasets. Lobban et al. (2004 & 2005); Gomez-de-Regil et al. (2014 & 2015); Cavelti et al. (2012a & 2012b); Gumley et al., (2006) and Karatzias et al., (2007); Watson et al. (2006), Fialko et al. (2006) and Freeman et al. (2013); Study 1 from Birchwood et al. (2005) and Iqbal et al. (2000) appeared to utilise the same or overlapping datasets to conduct different analyses.

Origins of sample

The location of studies was diverse and included Spain (n = 1), Pakistan (n = 1), Australia (n = 3), United Kingdom (n = 20), New Zealand (n = 1), Switzerland (n = 2), France (n = 1), Mexico (n = 2), United States of America (n = 1), and Northern Ireland (n = 1). The number of participants in each study ranged from 8 to 407 with a total of 3358 in the 33 studies. Participant mean ages ranged from 24 to 69 years, although age was not reported in four studies. The proportion of females in study samples ranged from 0% to 70%, although gender information was not reported in seven studies. Participants of included studies had a range of diagnoses within the psychosis spectrum disorders including schizophrenia, schizoaffective disorder, non-affective psychosis, delusions disorder, psychosis, first episode psychosis and bipolar. Participants were recruited from a mixture of inpatient and community settings. Twenty studies did not report ethnicity information. The 12 studies that reported ethnicity information varied in the level of diversity within samples.

Study design

All the included papers utilised a quantitative approach, no qualitative papers met the inclusion criteria. The aims of the different studies were broad which reflects the exploratory nature of this review. Eight studies used a combination of cross-sectional and longitudinal or intervention outcome analyses. Therefore, a total 26 studies included cross-sectional analyses, nine included longitudinal analyses and seven included analyses related to interventions. Of the intervention studies, five studies utilised a randomised controlled trial design and two utilised a cohort intervention design. Longitudinal analyses ranged from two weeks to 30 months. Intervention follow-up periods ranged from 2-8 weeks up to five years. Three of the studies included assessed psychoeducation-based interventions and four assessed CBTp, with one study assessing CBT targeted at persecutory delusions only.

Measures of Illness perception

Illness perceptions were described using a variety of terms, these included; appraisals about illness, beliefs about illness, illness cognitions, illness appraisals, subjective illness beliefs, cognitive representations, beliefs about mental health problems, attitudes toward psychosis, attitudes towards symptoms, illness beliefs and explanatory models of illness. Illness perceptions were assessed using a range of measures, those based on the SRM framework included: Illness Perception Questionnaire for Schizophrenia (IPQS; Lobban, Barrowclough, & Jones, 2005), Modified Illness Perception Questionnaire (M-IPQ, modified from Weinman et al., 1996), Revised Illness Perception Questionnaire (R-IPQ; revised from the IPQ, Weinmain 1996), Illness Perception Questionnaire Revised (IPQ-R; Moss-Morris et al. 2002), Brief Illness Perceptions Questionnaire (BIPQ, Broadbent et al., 2006). Those based on other psychological theories included: Personal Beliefs about Illness Questionnaire (PBIQ; Birchwood et al.,1993), Illness Cognitions Scale (ICS; Berk et al., 2007), Short Explanatory Model Interview version 3.0 (SEMI; Mirza et al., 2006), modified version of the Short Explanatory Model Interview (SEMI; Lloyd et al,,1998) and Soskis scale of attitude towards illness. (Soskis and Bowers, 1969). Some of these measures were modified or adapted for the study, for example, by changing wording to be appropriate for the sample or by adding additional questions. Studies also varied in whether total or subscale scores were used in analyses. Studies of the PBIQ measure used varying descriptions of the same subscales. For simplicity, consistent subscale names have been employed to describe results in this review throughout. These are: control (perceived control over illness or entrapment by illness), shame (perception of need for containment and social marginalisation), loss (expectations or perceived loss of autonomy, social/valued role), humiliation (internalisation and acceptance of stigmatising aspects of illness, humiliating devaluation of self) and self as illness (attribution of illness to self rather than illness, belief that illness is a reflection of the self rather than something which the individual has).

Study outcomes of interest

The included studies assessed a range of outcomes which were captured using different methods (see Table 1.1). Twenty studies included outcomes related to psychological distress, including anxiety, depression, hopelessness, self-harm and suicidal behaviour. Ten studies included outcomes related to quality of life, including subjective wellbeing, satisfaction with mental health, self-rated mental health and quality of life. Eight studies included functioning outcomes, which were assessed either overall or in relation to specific dimensions e.g. life skills, activity level, social and occupational, or social. Nineteen studies included measures of positive psychosis symptoms which were assessed using a range of measures. When available, findings relating to positive symptoms specifically were reported (Tables 1.2-1.4). If only composite scores of positive and negative scores were available, findings were reported in relation to the combined score. Engagement outcomes in relation to psychological interventions (psychoeducation or CBTp) were included in three studies which included adherence of participants in therapy (none, partial or full participation in active therapy techniques), self-reported engagement (e.g. actively working on mental health problems) and completion of intervention (versus non-completion). Change in illness perceptions over time or during interventions was assessed in four studies.

Risk of bias within studies

Sixteen of the studies were rated as weak quality, twelve were of moderate quality and five were of strong quality. A summary of the quality of each included study as assessed by each criterion of the QATQ is presented in Table 1.5 (more detailed information from the quality assessment is included in Appendices C and D). Studies were most frequently given lower ratings due to cross-sectional design, selection bias from recruitment from clinical services with a relatively high percentage of individuals who were approached to take part but declined, withdrawal and dropout rates not reported, and no description of assessment or controlling for confounders.

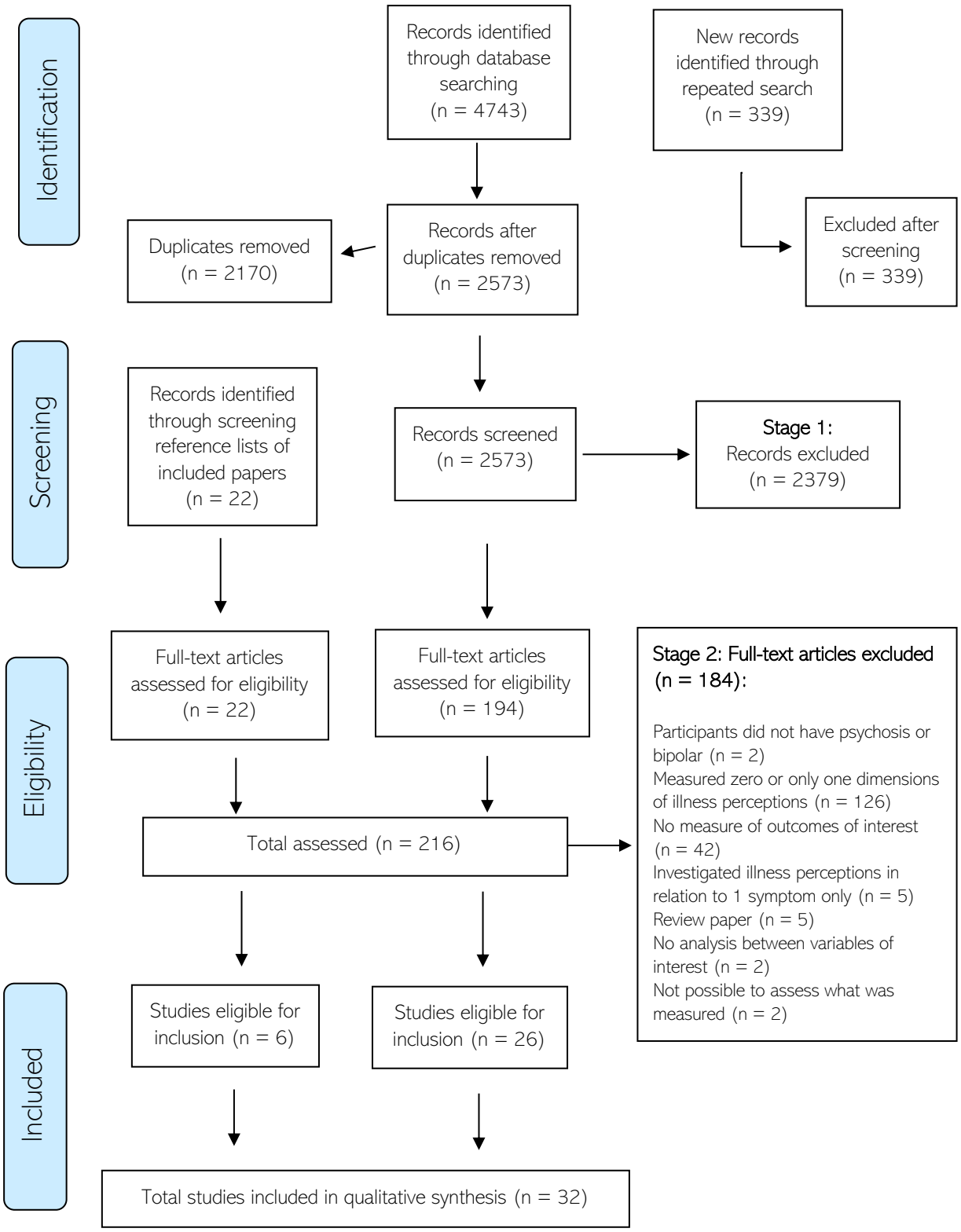

Figure 1.1 CONSORT diagram illustrating results of study selection

Table 1.1 Characteristics and methods of included studies

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Acosta 2013 Spain	To improve our understanding about the relationships between patients' cognitions about their illness and suicide risk.	CS (data from prospective case-control study collected < 1 year prior)	Schizophrenia, outpatient clinic (1 year after admitted to acute psychiatric unit) 31.1 years (8.1) 19-55, 25% female, ethnicity information not reported	60	PBIQ: subscale and total scores Suicidal behaviour (self-inflicted non-fatal injury with intent v none) Depression (CDS) Hopelessness (BHS)	Mann-Whitney U, correlations, multiple regression
Awan 2017 Pakistan	To investigate the explanatory models of illness in patients suffering from Schizophrenia and the role of educational intervention, which is expected to be beneficial for patients, caregivers and mental health professionals.	RCT: Educational Intervention v TAU (3 months)	Schizophrenia, inpatient setting 30.5 years (9.4), 23% female, ethnicity information not reported	103	SEMI Symptoms (PANSS, BPRS) Functioning (GAF) Change in illness perceptions over time	Chi-square
Berk 2013 Australia	To examine the associations between illness cognitions measured by the ICS and clinical variables in a cohort of individuals with a current diagnosis of bipolar disorder or schizoaffective disorder.	Longitudinal (24 months) + CS analysis	Bipolar I disorder or schizoaffective disorder, outpatient setting Age, gender, ethnicity information not reported	89	The Illness Cognitions Scale (ICS) Symptoms (CGI-BP, YMRS) Depression (HAMD21) Functional health (SF-36 physical component) Wellbeing (SF-36 mental component) QOL (EQ-5D)	Correlations, Regression
Birchwood 1993 UK	To explore the relationship between depression in chronic psychosis and (a) acceptance or rejection of mental illness, (b) perceived controllability of illness and (c) acceptance by the patient of these cultural stereotypes of mental illness.	CS, Depression v no depression	Schizophrenia or bipolar, receiving therapy Depression = 43.0 years (14.3), No depression = 48.3 years (14.3) Depression group contained 22% females, 18.5% White British, 42% Caribbean British, Asian British17% of sample	84	PBIQ: subscale scores Depression (BDI)	Test of difference, discriminant function

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Birchwood 2005 Study 1 UK	To establish the course patterns of post psychotic depression and their link with symptoms and appraisals of psychosis.	Longitudinal (3 months)	Followed up after acute psychotic episode Age, gender, ethnicity data not reported	105 26	PBIQ: subscale scores Depression (BDI)	MANOVA
Birchwood 2005 Study 3 UK	To assess whether depression in acute schizophrenia arises from similar psychological processes to those identified in post psychotic depression and in auditory hallucinations.	CS	First episode psychosis Age, gender, ethnicity data not reported	26	PBIQ: subscale scores Depression (CDSS)	Correlations
Broadbent 2008 New Zealand	To assess illness perceptions in patients with severe mental illness who were also high users of services and to investigate their association with functioning, attitude to medication, visits to GP and needs.	CS	Psychotic disorder with high service use 40.86 years (10.59). 54% female, 42% European, 46% Maori, 5% Pacific Islander, 1% Asian, 3% other ethnicities	203	BIPQ: individual items/subscale scores Functioning (GAF)	Correlations
Cavelti, 2012a Switzerland	To investigate the mechanisms underlying the detrimental association of insight and depressive symptoms as well as potential protective factors.	CS	Schizophrenia or schizoaffective disorder, outpatient setting 44.8 years (11.76), 35% female, ethnicity data not reported	142	IPQS (Acute/Chronic, Consequences and Treatment control subscales analysed separately) German version Symptoms (PANSS) Depressive symptoms (CDSS, BDI-II, Emotional regulation subscale of SWN-K)	SEM

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Cavelti 2012b Switzerland	To analyse the psychometric properties of the German version of the IPQS	CS	Schizophrenia or schizoaffective disorder, outpatient setting 44.3 years (11.78), 32% female, ethnicity information not reported	128	IPQS: subscale scores, excluding Cause (German version) Symptoms (PANSS: positive subscale and total score general psychopathology) Depression (CDSS, BDI-II) Subjective wellbeing while under antipsychotic treatment (SWN-K)	Correlations, multiple regression
Drury 2008 UK	To examine 5-year outcomes of a cohort of patients who had received a multi-component CBT intervention during an acute episode of non-affection psychosis	RCT 5 year FU, CBT v recreational activities and support (control)	Non-affective psychosis, inpatient setting at time of recruitment 32.5 years, 35% female 62% White, 15% Asian, 23% African-Caribbean	34	PBIQ: subscale scores Change in illness perceptions assessed between groups over time	ANCOVA
Etain 2018 France	A feasibility, or 'proof of principle' study to assess individuals with BD from the point of acceptance of an invitation to participate in psychoeducation (PE) through to dropout from or completion of a group programme delivered in a day-to-day clinical setting and that included patient-focused outcomes	Cohort, TAU PE intervention (3 months) pre v post	Bipolar, outpatient setting, Completers (n = 103): 42 years (12), 56% female Information for completers (n = 56) not reported, but not significantly different to completers, ethnicity information not reported	156	BIPQ total score (revised version with additional question: how much agree with BP diagnosis?) Engagement (completers v non completers) Social functioning (QFS) Change in illness perceptions over time	t tests, correlations, multiple regression, mediation (PROCESS model)

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Fialko 2006 UK	To examine suicidal ideation in psychosis in relation to affective processes, the multidimensional nature of positive symptoms, demographic and clinical variables.	CS (compared no, mild and severe suicidal ideation)	Schizophrenia, schizo-affective, delusional disorder, inpatient and outpatient settings, PRP trial (during relapse of positive symptoms) 37.6 years (10.9), 29% female, 75% White, 10% Black-African, 8% Black-Caribbean, 3% Black-Other, 2% Indian, 7% Other	277	R-IPQ: 3 subscales (Timeline, Cure-control, Consequences) Symptoms (PANSS, PSYRATS, SAPS) Suicide/self-harm (SCAN item 6.11) Suicide attempts (clinical records)	ANOVA, post hoc Bonferroni, correlations
Freeman 2013 UK	To examine differences in illness perceptions between those who went on to be fully engaged in therapy, those who did not engage with active therapeutic techniques, and those who did not attend sessions.	Cohort CBT intervention (9 months, 12-20 sessions) full v partial v no therapy	Non-affective psychosis, PRP trial (those allocated to CBT) No therapy: 38.1 years (12.5), Partial therapy: 39.8 years (10.4), Full therapy: 39.5 years (9.2); 27% female, 68% White, 9% Black-African, 9% Black-Caribbean, 4% Indian, 10% Other	92	Modified IPQ: 5 subscales (Causes, Symptoms, Timeline, Cure-control, Consequences) Adherence (R-CTPAS) Symptoms (PANSS)	Chi-squared test, ANOVA
Gomez-de-Regil 2014 Mexico	To examine the association of illness course with QoL in a sample of Mexican patients with psychosis and propose a model where illness perception might play a mediating role between illness course and its effect on QoL.	CS	Schizophrenia or schizophrenia-spectrum psychoses, recruited from hospital through clinical records review 35.9 years (10), 56% female, ethnicity information not reported	61	BIPQ: 3 subscales, cognitive (5 items), emotional (2 items) and comprehensibility dimensions (1 item) Quality of Life (CSCV) Symptoms (only negative or 2 ≥ positive symptoms: present or absent)	Correlations, multiple mediation boostrap

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Gomez-de-Regil 2015 Mexico	To assess insight and illness perception in a sample of Mexican patients who have experienced psychosis and analyse how insight and illness perception relate to each other and to measures of clinical status (i.e., positive and negative symptoms, general psychopathology, depression, anxiety).	CS	Schizophrenia or other schizophrenia-spectrum psychotic disorder, recruited from local hospital 35.9 years (10), 56% female, ethnicity information not reported	61	BIPQ: 3 subscales, cognitive (5 items), emotional (2 items) and comprehensibility dimensions (1 item) Symptoms (PANSS) Depression (CDS) Anxiety (BAI)	Correlations
Gumley 2006 UK	To investigate the association between relapse, beliefs about illness and self-esteem. To investigate whether CBT reduces negative beliefs about psychosis and improves self-esteem in 12 months.	RCT: CBT v TAU (12-month FU)	Schizophrenia or related condition, outpatient setting CBT = 35.8 (9.6), 25% TAU = 36.7 (10.1), 29% Relapsed: 33.6 (8.3), 29% Not relapsed = 37.2 (10.2), 26% female, ethnicity information not reported	144	PBIQ: subscale scores Symptoms (PANSS) Change in illness perceptions over time	Regression
Iqbal 2000 UK	To apply their cognitive framework to post psychotic depression and chart the appraisal of self and psychosis and their link with the later emergence of post psychotic depression.	Longitudinal (12 month FU) + CS analysis	Schizophrenia, inpatient setting 33.52 years, other information not reported	105	PBIQ: subscale scores Depression (DEQ)	MANOVA
Karatzias 2007 UK	To test the hypothesis that greater negative beliefs about illness and lower self-esteem will be significantly associated with the presence of anxiety or affective comorbidity in a sample of persons diagnosed with schizophrenia	CS	Schizophrenia spectrum disorder, outpatient setting (part of Gumley 2006 trial) 36.5 years (9.7), 28% female, ethnicity information not reported	138	PBIQ: subscale scores Anxiety disorders: present or absent Affective disorders: present or absent	Logistic Regression

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Lobban 2004 UK	To test the SRM in the context of schizophrenia and examine appraisals about psychosis more closely.	Longitudinal (6-month FU) + baseline CS analysis	Schizophrenia, schizoaffective, psychosis, paranoid psychosis or delusional disorder, community setting 38.8 years (10.4), other information not reported	124	IPQS: subscale scores Anxiety (HADS) Depression (HADS) Functioning (GAF) Quality of Life (MANSA subscale) Satisfaction with mental health (MANSA subscale)	Multiple regression
Lobban 2005 UK	To validate a modified version of the recent IPQ-R for people with a diagnosis of schizophrenia.	CS and test-retest analysis (2 weeks and 6 months)	Schizophrenia or schizoaffective disorder 38.8 years (10.4), other information not reported	124	IPQS: subscale scores Symptoms (PANSS) Anxiety (HADS) Depression (HADS)	Correlations
Lobban 2013 UK	To measure and describe the nature of beliefs that people with bipolar hold about their mood swings and test the hypotheses that these beliefs are associated with significant differences in important clinical outcomes measured longitudinally over a 24 weeks follow-up period.	Longitudinal (24 weeks) + CS baseline analysis	Bipolar, recruited from community mental health teams (data from cluster RCT feasibility of training care coordinators to deliver enhanced relapse prevention) 45 (10), 67% female, ethnicity not reported	91	BIPQ: individual items/subscale scores. Additional questions: personal effort, cause internal, self blame Symptoms (time to relapse, Early Warning Signs Checklist) Depression (HDRS, LIFE-II weekly ratings) The Social and Occupational Functioning Assessment Change in illness perceptions over time	Contingency tables, Bangdiwala statistic, proportional odds models, Cox proportional hazard models
Maguire 2016 Australia	To the explore the correlates of a single-item Self-Rated Mental Health Questionnaire in people with Schizophrenia, in order to achieve a better understanding of what it is measuring.	CS	Schizophrenia, recruited from mental health care settings 36.1 (9.7) 16-62, 30% female, ethnicity not reported	71	BIPQ: individual items/subscale scores Mental health (Single-item SRMHQ rated in 5-point Likert scale)	Correlations, linear regression

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Marcus 2014 UK	To prospectively investigate the ability of the modified IPQ measure to: i) predict clinical outcome in participants receiving a brief cognitive behavioural intervention, and ii) to differentially predict response for an intervention group compared to a no-intervention control group.	Brief CBT targeted for persecutory delusions (4-8 weeks; RCT n = 34, case series n = 6) v control no therapy (n = 16) + CS baseline analysis	Schizophrenia spectrum psychosis, outpatient setting recruited from the last cohort of the Cognitive Mechanisms of Change in Delusions study 42.4 (10.8), 32% female, 54% White British/Irish/ Other, 39% Black Caribbean/African/ Mixed/Other, 7% Asian Mixed/Other	56	MIPQ: 3 subscales Symptoms: Paranoia (Paranoid Thought Scales, 5 visual analogue ratings 0-100%, mean = overall paranoia score) Conviction (rating how much they believed it 0-100%) Belief Inflexibility (reverse scored ratings: extent to which considered it possible were mistaken in delusion 0-100%)	Correlations, regression
McCabe 2004 UK	To assess the stability of over time of explanatory models of illness among people with schizophrenia.	Longitudinal (12 months)	Schizophrenia Age and gender information not reported, 13% UK White, 38% were African-Caribbean, 38% were West African and 13% Bangladeshi	8	SEMI Change in illness perceptions over time	Frequencies of coded responses, kappa interrater reliability
McGlashan 1981 USA	To investigate the relationship between attitude and post hospital adjustment in schizophrenia	CS at follow up (12 months after admission)	Schizophrenia, inpatients receiving treatment: psychotherapy (individual, group, family), occupational and recreational therapy, active therapeutic milieu, no pharmacotherapy 24 years (SD not reported) 17-54, 57% female, 93% White, 7% Black	30	Soskis Scale of Attitude Towards Illness Symptoms (PSE; Present State Examination) Global psychopathology (measure not reported) Fullness of Life Overall level of functioning (measures not reported)	Pearson correlations

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Moriarty 2012 UK	To clarify the relationship of perceived stigma, illness perceptions and insight to variation in activity levels.	CS	Schizophrenia spectrum psychosis, community setting 45.5 years (11.9), 34% female, 46% White British, 14% Black British, 16% Black African, 8% Black Caribbean, 2% Asian, 14% Other	50	BIPQ total score Symptoms (PANSS) Anxiety (HADS) Depression (HADS) Activity level (week-long diary)	Correlations, regression
Proudfoot 2012 Australia	To examine the comparative effectiveness of an online psychoeducation program for people diagnosed with bipolar disorder within the previous 12 months, completed alone or with adjunct peer support, on symptoms and perceived control of illness.	RCT, Online bipolar education v education + peer support v control (simple facts + daily mood monitoring) (6 month FU)	Bipolar BEP = 66.9 years BEP + IS = 73.1 years Control = 69.4 years 70% female, ethnicity information not reported	407	BIPQ: Personal Control and Understanding subscales/items Change in illness perceptions assessed during intervention and between groups	ANCOVA
Rooke 1998 UK	To determine (a) stability of depression and key appraisals of psychosis, (b) whether any changes in depression are linked to changes in these appraisals, and (c) whether sense of control in psychotic illness has links with the experience of psychiatric management, which could be seen as disempowering and reinforce a sense of helplessness.	Longitudinal (30 months)	Schizophrenia 42.1 years (12.7), 22% female, 11% Asian, 26% Black Caribbean, 62% White	47	PBIQ: subscale scores Depression (BDI) Symptoms (PSE and SANS) Change in illness perceptions over time	Correlations, ANOVA, regression

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Shah 2009 UK	To investigate whether individuals' beliefs about their psychosis are associated with engagement in treatment in a forensic setting. To investigate whether dimensions of the IPQS are associated with actual treatment engagement, rather than attitudes towards medication.	CS	Schizophrenia, schizoaffective disorder or psychosis, secure forensic setting with individual program of care to reduce mental health difficulties prevent reoffending and support reintegration 36 years (11.2), 0% female, ethnicity not reported	30	IPQS: subscale scores Self-reported engagement (URICA, Action score in relation to addressing mental health difficulties, assumption it would be sensitive to engagement in therapy) *(Service Engagement Measure not included in review as not specific to engagement in therapy i.e. includes medication adherence)*	Correlations, regression
Stainsby 2010 UK	To investigate whether attitudes and beliefs about symptoms more important than symptom severity in recovery from psychosis.	Longitudinal (2 years) + CS baseline analysis	Psychotic disorder 41 years (13.2), 28% female, 42% White British, 20% Black British Caribbean, 14% Black British African	31	IPQS: subscale scores Symptoms (BPRS) Quality of life (MANSA) Functioning (Life skills Profile; LSP) *(Engagement measure not included as relates to service engagement)*	Correlations, regression
Theodore 2012 UK	To examine relationships between subjective QoL, illness beliefs and symptom factors, and to determine which of these factors predicted subjective QoL in an early psychosis sample.	CS	Psychosis, Early intervention service caseload (outpatient and inpatient) 26 years (4.4) 19-35, 30% female, 36% White British, 12% White Other, 3% Mixed, 7% Asian/Asian British Bangladeshi, 33% Black or Black British, 7% Other	81	IPQS: subscale scores Quality of life (MANSA)	Correlations, regression

First Author, year & location	Aim(s) of study	Study design	Population Sample: mean age (SD) range, % female, ethnicity	n	Illness Perceptions Measure Outcomes of interest (measures)	Statistical Analysis
Watson 2006 UK	To examine the relationship between illness perception, emotional response and attitudes to medication in people with a recent relapse of their psychosis.	CS (baseline measures from RCT)	Non-affective psychosis (schizophrenia, schizo-affective psychosis, delusional disorder, inpatient and outpatient settings (PRP trial) 39.1 years (10.6), 28% female, 68% White, other ethnicity information not reported	100	MIPQ: subscale scores Symptoms observer rated (PANSS) Depression (BDI-II) Anxiety (BAI)	Correlations, regression
White 2007 Northern Ireland	To investigate how psychiatric symptom levels and beliefs about illness might be linked to hopelessness in 100 patients with schizophrenia.	CS	Schizophrenia 39.4 years (11.2), 22% female, 100% White	100	PBIQ: subscale scores Depression (CDSS) Hopelessness (BHS) Symptoms (BPRS)	Correlations, MANCOVA, regression

BDI: Beck Depression Inventory; BHS: Beck Hopelessness Scale; BIPQ: Brief Illness Perception Questionnaire; BPRS: Brief Psychiatric Rating Scale; CALPAS-P: California Psychotherapy Alliance Scales; CDSS: Calgary Depression Scale for Schizophrenia; CDS: Calgary Depression Scale; CS: Cross-sectional; DEQ: Depressive Experiences Questionnaire; DUP: Duration untreated psychosis; FU: Follow up; GAF: Global Assessment of Functioning; HDRS: Hamilton Depression Rating Scale; HLOC: Health Locus of Control; ICS: Illness Cognitions Scale; IP: Illness Perceptions; IPQS: Illness Perceptions Questionnaire for Schizophrenia; LIFE-II: Longitudinal Interview Follow-up Evaluation; LSP: Life Skills Profile; MIPQ: Modified Illness Perception Questionnaire; MOS-SSS: MOS Modified Social Support Survey; PANSS: The Positive and Negative Syndrome Scale; PBIQ: Personal beliefs about illness questionnaire-revised; PPD: Post-psychotic depression; PSE: Present State Examination; QOL: Quality of Life; RCT: Randomised Controlled Trial; SANS: Scale for the Assessment of Negative Symptoms; SD: Standard Deviation; SEMI: Short Explanatory Model Interview;SF-36: 36-item Short Form Health Survey; SOCRATES: Stages of Change Readiness and Treatment Eagerness Scale; TAU: Treatment as usual; URICA: University of Rhode Island Change Assessment Scale

Table 1.2 Findings from cross-sectional studies (clustered by illness perception measure)

Study IP Measure	Summary of findings	Relationships between dimensions of illness perceptions and outcomes				
		Distress	QOL	Functioning	Psychosis symptoms	Engagement
Acosta 2013 PBIQ: subscale and total scores	Total score correlated with hopelessness (rho = 0.60***) and depression (rho = 0.38**). Perceptions of having less control over illness (rho = 0.38**), more loss (rho = 0.38**), and higher levels of humiliation (rho = 0.37**) correlated with higher levels of depression. Perceptions of having less control over illness (rho = 0.56***) more loss (rho = 0.47***), and higher levels of humiliation (rho = 0.56***) and self as illness (rho = 0.30, p = 0.02) correlated with higher levels of hopelessness. Regression: Loss (β = 0.43***) and humiliation (β = 0.28*) subscales independently associated with depression. (r^2 = 0.39, SE = 1, 91, F (2,57) = 17.9***). Loss (β = 0.40***) and humiliation (β = 0.42***) subscales independently associated with hopelessness (r^2 = 0.50, SE = 3,40, F ($_{2,57}$) = 28.5***). No sig differences in illness perceptions of those with or without previous suicide attempts.	Control[C] Loss[CR] Humiliation[CR] Self as illness[C] Total score[C]				
Birchwood 1993 PBIQ: subscale scores	Patients with depression expressed more negative illness perceptions than those without depression for all subscales (control F = 33.4, <0.001; loss F = 19.0***; shame F = 15.3***; self as illness F = 6.3*; humiliation F = 12.8**). Less belief in control over illness was most strongly associated with depression.	Control^ Shame Loss Humiliation Self as illness				
Birchwood 2005 (Study 3) PBIQ: subscale scores	Greater loss, shame and of having less control were correlated with being more likely to report depression (r = 0.66, 0.58 and 0.59 respectively; all p < 0.001), independent of positive symptoms.	Control Shame Loss				
Karatzias 2007 PBIQ: subscale scores	Perceptions of having less control of psychosis were independently associated with presence of an anxiety or affective comorbid condition (β = 0.43, p = 0.001).	Control				
Rooke 1998 (Cross-sectional analysis) PBIQ: subscale scores	Perceptions of less control over illness were positively correlated with presence of hallucinations and delusions (rho = 0.39 and rho = 0.41, p < .05, respectively), except grandiose and religious delusions which correlated with perceptions of more control.				Control	

Study IP Measure	Summary of findings	Relationships between dimensions of illness perceptions and outcomes Distress	QOL	Functioning	Psychosis symptoms	Engagement
White 2007 PBIQ: subscale scores	Higher levels of symptoms correlated with perceptions of less control (r = 0.49***), higher self as illness (r = 0.43***), more loss (r = 0.47***), more humiliation (r = 0.42***) and shame (r = 0.35***). Higher levels of depression correlated with perceptions of less control (r = 0.60***), higher self as illness (r = 0.36***), more loss (r = 0.51***) and more humiliation (r = 0.44***). Higher levels of hopelessness correlated with perceptions of less control (r = 0.57***), higher self as illness (r = 0.36***), more loss (r = 0.57***), more humiliation (r = 0.42***) and shame (r = 0.47***). *MANCOVA:* lower control (F = 6.46, df = 1,97, p = 0.013), higher self as illness (F = 5.65, df = 1,97, p = 0.019), more loss (F = 13.39, df = 1,97, p 0.001) and more shame (F = 24.20, df = 1,97, p = 0.013 were associated with more hopelessness, after controlling for level of depression. Stepwise regression: only perceptions of shame was independently associated with higher levels of hopelessness (β = 0.29, p <0.001).	Control[CM] Loss[CM] Shame[CMR] Humiliation[C] Self as illness[CM]			Control[C] Loss[C] Shame[C] Self as illness[C] Humiliation[C]	
Iqbal 2000 (Cross-sectional analysis) PBIQ: subscale scores	At the PPD stage (PPD group was showing depression), all subscales were significantly more negative in those with PPD compared to the non-PPD group (control: F = 27.5***; shame: F = 10.3**; humiliation: F = 8.0**; self as illness: F = 9.4**; loss: F = 12.8**).	Control Shame Loss Humiliation Self as illness				
Cavelti 2012a IPQS: subscale scores	Relationship between insight and depressive symptoms was fully mediated by participants' perception that their illness is chronic (from β = 0.442, P = 0.001 to β = 0.225, P = 0.157) and with disabling consequences (from β = 0.462, P = 0.001 to β = 0.151, P = 0 .249) and supressed by the expectation of symptom control due to treatment (from β = 0.435, P = 0.001 to β = 0.577***).	Timeline chronic Consequences Treatment control				
Shah 2009 IPQS: subscale scores	Beliefs in a chronic (r = 0.51, p = 0.004) and relapsing course (r = 0.41, p = 0.026) and in the treatability of the conditions (r = 0.71***) were significantly correlated with higher self-reported engagement.					Timeline chronic Timeline cyclical Treatment control

Study IP Measure	Summary of findings	Relationships between dimensions of illness perceptions and outcomes Distress	QOL	Functioning	Psychosis symptoms	Engagement
Stainsby 2010 (Baseline analysis) IPQS: subscale scores	Perceptions of fewer negative consequences (r = −0.34, p = 0.021) and better coherence (r = −0.46, p = 0.001) were correlated with better QoL. In regression analyses, symptom severity accounted for little variance in QoL (Adj R^2 = 0.024), beliefs about consequences and coherence increased the variance ($F_{3,43}$ = 5.67, p = 0.002, Adj R^2 = 0.284). Fewer negative consequences was a significant independent predictor of QoL (SB = −0.387, p = 0.006), coherence beliefs approached significance. No associations were found between illness perceptions and impairment in life skills.		Consequences[CR] Coherence[C]	X		
Cavelti 2012b IPQS: subscale scores	Higher awareness of symptoms was correlated with poorer subjective wellbeing while under antipsychotic treatment (r = 0.26**) and higher levels of depression (CDSS r = -0.20*). Attribution of symptoms to mental health problems correlated with worse severity of positive symptoms (r = 0.26) and poorer subjective wellbeing while under antipsychotic treatment (r = 0.22*). Perceptions of a more chronic timeline correlated with worse subjective wellbeing (r = -0.33**) and depression (CDSS r = 0.19*, BDI-II r = 0.26**). Perceptions of a cyclical timeline correlated with worse subjective wellbeing (r = -0.19*) and depression (CDSS r = 0.21*, BDI-II r = 0.28**). Perceptions of more negative consequences correlated with worse subjective wellbeing (r = -0.62**) and depression (CDSS r = 0.26**, BDI-II r = 0.45**). Perceptions of lower personal control correlated with more severe positive symptoms (r = -0.30**) and depression (CDSS r = 0.19*, BDI-II r = 0.20*). Beliefs that treatment is likely to be helpful correlated with less severe positive symptoms (r = -0.24**), better subjective wellbeing (r = 0.34**) and less depression (BDI-II r = 0.20*). Perceptions of a more coherent understanding of illness correlated with better subjective wellbeing (r = -0.46**) and less depression (BDI-II r = 0.36*). Perceptions of a more negative emotional response correlated with more severe positive symptoms (r = 0.23**), worse subjective wellbeing (r = -0.63**) and depression (CDSS r = 0.25**, BDI-II r = 0.47**). *Regression*: Belief that treatment is likely to be helpful was associated with less severe total score symptoms (SB = -0.20*) and better subjective wellbeing (SB = 0.36**). Perceptions of more negative consequences (SB = -0.39**), a less coherent understanding of illness (r = -0.36*) and a more negative emotional response (r = -0.40***) were independently associated with poorer subjective wellbeing.	Identity[C] Timeline chronic[C] Timeline cyclical[C] Consequences[C] Personal control[C] Treatment control[C] Coherence[C] Emotional response[C]	Identity[C] Causes[C] Timeline chronic[C] Timeline cyclical[C] Consequences[CR] Treatment control[CR] Coherence[CR] Emotional response[CR]		Causes[C] Personal control[C] Treatment control[CR]	

Study IP Measure	Summary of findings	Relationships between dimensions of illness perceptions and outcomes Distress	QOL	Functioning	Psychosis symptoms	Engagement
Lobban 2004 *(Baseline analysis)* IPQS: subscale scores	Higher identity of symptoms correlated with worse anxiety, depression, quality of life and satisfaction with mental health (r = 0.36**, 0.27**, -0.29**, -0.28**, -0.20*, respectively). Attribution of symptoms to mental health problems correlated with worse anxiety (r = 0.19*), attribution to medication side effects correlated with better global functioning (r = 0.19**), and attribution to other factors correlated with more satisfaction with mental health (r = 0.21*). Perceptions of a more chronic timeline correlated with worse anxiety, depression, quality of life, satisfaction with mental health and functioning (r = 0.31**, 0.28**, -0.24*, -0.30**, -0.27**, respectively). Perceptions of a cyclical timeline correlated with worse anxiety, depression, quality of life and satisfaction with mental health (rho = 0.37**, 0.45**, -0.26**, -0.19*, respectively). Perceptions of more severe consequences correlated with worse anxiety, depression, quality of life, satisfaction with mental health and functioning (r = 0.47**, 0.54**, -0.61**, -0.48**, -0.41**, respectively). Perceptions of less personal control correlated with worse quality of life, satisfaction with mental health and functioning (r = 0.26*, 0.30**, -0.30**, respectively). Less belief in treatment being helpful correlated with worse anxiety, depression, quality of life, satisfaction with mental health and functioning (rho = -0.23*, -0.26**, 0.32**, -0.35**, 0.28**, respectively). Having a less coherent understanding was correlated with worse depression, quality of life, satisfaction with mental health and functioning (r = 0.32**, -0.22*, -0.23*, -0.20*, respectively). *Regression*: Identifying more symptoms predicted worse anxiety (SB = 0.21*). Attribution of symptoms to medication effects predicted better functioning (SB = 0.19*). Attribution to other factors predicted better satisfaction with mental health (SB = 0.21**). Perceptions of more severe consequences predicted worse anxiety, depression, quality of life, satisfaction with mental health and functioning (SB = 0.24*, 0.50**, -0.43**, -0.25**, -0.18*). Perceptions of having less personal control predicted worse quality of life (SB = 0.15*). Less belief in treatment as helpful predicted worse satisfaction with mental health (SB = 0.19*). Having a less coherent understanding predicted worse depression (SB = 0.22**).	Identity^{CR} Cause^{C} Timeline chronic^{C} Timeline cyclical^{C} Consequences^{CR} Treatment control^{C} Coherence^{CR}	Identity^{C} Cause^{CR} Timeline chronic^{C} Timeline cyclical^{C} Consequences^{CR} Personal control^{CR} Treatment control^{CR} Coherence^{C}	Cause^{CR} Timeline chronic^{C} Consequences^{CR} Personal control^{C} Treatment control^{C} Coherence^{C}		

Study IP Measure	Summary of findings	Relationships between dimensions of illness perceptions and outcomes				
		Distress	QOL	Functioning	Psychosis symptoms	Engagement
Lobban 2005 (Cross-sectional analysis) IPQS: subscale scores	Higher identification of symptoms was correlated with more severe symptoms, worse anxiety and depression (rho = 0.24**, 0.32**, 0.29**, respectively). Attribution of symptoms to mental health problems was correlated with worse anxiety (rho = 0.21*). Attribution to medication side effects or other factors correlated with less depression (rho = -0.19*), attribution to other factors correlated with less anxiety (rho = -0.19*). Perceptions of a chronic timeline correlated with worse severity of symptoms, anxiety and depression (rho = 0.31**, 0.28**, 0.30**). Perceptions of a cyclical timeline correlated with worse severity of symptoms and anxiety (rho = 0.32**, 0.37**). Perceptions of more negative consequences were correlated with worse severity of symptoms, anxiety and depression (rho = 0.32**, 0.26**, 0.46**). Perceptions of more treatment control correlated with less anxiety and depression (rho = -0.23*, 0.26**). Perceptions of a less coherent understanding correlated with worse depression (rho = 0.24**). A strong negative emotional response correlated with worse symptoms, anxiety and depression (rho = 0.32**, 0.60**, 0.59**, respectively).	Identity Cause Timeline chronic Timeline cyclical Consequences Treatment control Coherence Emotional response			Identity Timeline chronic Timeline cyclical Consequences Emotional response	
Shah 2009 IPQS: subscale scores	Beliefs in a chronic (r = 0.51, p = 0.004) and relapsing course (r = 0.41, p = 0.026) and in the treatability of the conditions (r = 0.71***) were significantly correlated with higher self-reported engagement.					Timeline chronic Timeline cyclical Treatment control
Stainsby 2010 (Baseline analysis) IPQS: subscale scores	Perceptions of fewer negative consequences (r = −0.34, p = 0.021) and better coherence (r = −0.46, p = 0.001) were correlated with better QoL. In regression analyses, symptom severity accounted for little variance in QoL (Adj R^2 = 0.024), beliefs about consequences and coherence increased the variance ($F_{3,43}$ = 5.67, p = 0.002, Adj R^2 = 0.284). Fewer negative consequences was a significant independent predictor of QoL (SB = −0.387, p = 0.006), coherence beliefs approached significance. No associations were found between illness perceptions and impairment in life skills.		Consequences[CR] Coherence[C]	X		

Study IP Measure	Summary of findings	Relationships between dimensions of illness perceptions and outcomes				
		Distress	QOL	Functioning	Psychosis symptoms	Engagement
Theodore 2012 IPQS: subscale scores	Better quality of life correlated with higher perceived control of mental health problems by treatment (r = 0.29, p = 0.009), less reported negative consequences of psychosis (r = -0.35, p = 0.002) and less negative emotional response (r = -0.26, p = 0.018). Higher perceived treatment control (β = 0.231, p =0.03) was an independent predictor in regression analysis, controlling for anxiety and depression. Perceived negative consequences approached significance (β = -0.239, p = 0.07).		Consequences[C] Treatment control[CR] Emotional response[C]			
Fialko 2006 R-IPQ: 3 subscales	Suicidal ideation was associated with more negative perceptions of the consequences of the illness (F = 10.036***), expectation that it would last a long time (F = 6.797, p = 0.001) and less optimistic about the controllability and curability of it (F = 9.904***). Those without suicidal ideation were significantly more optimistic about consequences (p < 0.001), those with severe ideation perceived themselves as having less control over their illness than other groups (p = 0.008). Timeline subscale correlated significantly with illness duration (r = 0.173, p = 0.005). Timeline, cure-control and consequences subscales correlated significantly with symptom severity (r = 0.224 - 0.338***).	Timeline Consequences Cure/control			Timeline Consequences Cure-control	
Broadbent 2008 BIPQ: item scores	Better functioning was associated with higher perceptions of personal control (rho = 0.21***) and reported less identity of symptoms associated with their illness; rho = 0.16*).			Personal control Identity		
Gomez-de-Regil 2014 BIPQ: 3 subscales	Positive cognitive (r = -0.65***) and emotional representations (r = -0.42***) and a higher understanding of illness (r = 0.30*) were significantly associated with better quality of life. Association between residual symptoms and quality of life was fully mediated by cognitive representations (95% CI -0.38 – -0.020).		Emotional[C] Cognitive[CM] Comprehensibility[C]			
Gomez-de-Regil 2015 BIPQ: 3 subscales	More negative cognitive representations of illness were significantly related to more severe psychotic symptoms (r = 0.44***), and higher levels of anxiety (r = 0.27*) and depression (r = 0.49***). More negative emotional representations of illness were significantly related to more severe psychotic symptoms (r = 0.35**), and higher levels of anxiety (r = 0.35**) and depression (r = 0.42***). Comprehension dimension showed no significant associations.	Emotional dimension Cognitive dimension			Emotional dimension Cognitive dimension	

Study IP Measure	Summary of findings	Relationships between dimensions of illness perceptions and outcomes				
		Distress	QOL	Functioning	Psychosis symptoms	Engagement
Lobban 2013 *(Baseline analysis)* BIPQ: item scores (additional items)	Perceptions of less personal control over their mood swings (OR = 0.82, p = 0.018) and less personal effort to get well (OR = 0.81, p = 0.040) were associated with higher levels of depression.	Personal control Personal Effort				
Maguire 2016 BIPQ: item scores	*Correlations:* Worse self-rated mental health correlated with perception of worse consequences (r = -0.3, p = 0.04), emotional reaction (r = -0.3, p = 0.01), more identification of symptoms (r = -0.3, p = 0.03) and concern (r = -0.3, p = 0.03), less personal control (r = -0.5**) and longer timeline (r = -0.3, p = 0.02). *Regression:* Poor self-rated mental health was associated with perceptions of more negative consequences (β = 5.65, p = 0.01), lower personal control (β = -9.45**) and a less coherent understanding (β = -5.64, p = 0.01). Fair self-rated mental health was associated with perceptions of lower personal control (β = -3.25**), more symptom identity (β = 2.61, p = 0.04), feeling more concerned (β = 3.02, p = 0.04) and having a higher emotional response (β = 3.15, p = 0.02). Very good self-rated mental health was associated with a shorter timeline (β = -3.90**).		Identity^{CR} Timeline^{CR} Consequences^{CR} Personal control$^{CR\wedge}$ Coherence^{R} Concern^{CR} Emotional response^{CR}			
Moriarty 2012 BIPQ total score	No significant association was found between illness perceptions total score and activity levels (r = 0.05, p = 0.74; B = 0.21, p = 0.13).			X		
Marcus 2014 *(baseline analysis)* MIPQ: items and subscales	Lower perception of cure/control correlated with higher delusional distress (r = -0.3*) and belief inflexibility *(r* = -0.3, p = 0.02).				Cure/control	

Study IP Measure	Summary of findings	Relationships between dimensions of illness perceptions and outcomes				
		Distress	QOL	Functioning	Psychosis symptoms	Engagement
Watson 2006 MIPQ: subscale scores	Higher levels of symptoms rated by observer correlated with perceptions of higher symptom identity (r = 0.46**) and lower level of cure/control (r = 0.25*). Higher levels of anxiety and depression correlated with perceptions of higher symptom identity (r = 0.59**; r = 0.56**, respectively), longer timeline (r = 0.27**; r = 0.47**, respectively), worse consequences (r = 0.43**; r = 0.54**, respectively) and lower cure/control (r = -0.26**; r = -0.3**, respectively). No causal items correlated with level of depression. Attributing cause to state of mind correlated with higher levels of anxiety (rho = 0.27**). *Regression:* Illness perception constructs explained a substantial proportion of the variance in depression (46%) and anxiety (36%). Only perceived symptom identity was independently associated with anxiety (β = 0.50***). Perceived symptom identity (β = 0.39***), timeline (β = 0.25**) and consequences (β = 0.20*) were independently associated with depression.	Identity[CR] Timeline[CR] Consequences[CR] Cure/control[C] Causes[C]			Identity[C] Cure/control[C]	
Berk 2013 *(Cross-sectional analysis)* ICS: total score	More negative illness perceptions were correlated with worse depression symptoms (rho = 0.43, p < 0.0001) (but not mania), worse overall bipolar symptoms (rho, 0.35, p < 0.0009), worse functional health (r = 0.40, p < 0.0001) and wellbeing (r = 0.39, p < 0.0002) and quality of life (r = 0.46, p < 0.0001).	Total score	Total score	Total score	Total score	
McGlashan 1981 Soskis Scale of Attitude Towards Illness	A more positive attitude of the future in relation to illness was associated with high absence of symptoms (r = 0.57**), more fullness of life (r = 0.60**) and better overall functioning (r = 0.51**). However, appears to be driven by the future negative cluster which showed a similar pattern of correlations for fullness of life (r = -0.56**) and overall functioning (r = -0.50** therefore a positive attitude toward the future seemed less important than the absence of a negative attitude. Lower fullness of life was associated with more negative attitudes towards illness (r = -0.56**). The attitude clusters of integrate and isolate were not significantly related to outcome (p > 0.01).		Illness negative Future negative Future, positive minus negative	Future negative Future, positive minus negative	Future negative Future, positive minus negative	

Key: * p < 0.05; ** p < 0.01; *** p < 0.001; [C] = effect found in correlation analysis; [R] = effect found in regression analysis; [M] = effect found in mediation analysis; CI = confidence intervals; OR = odds ratio;

Table 1.3 Findings from longitudinal studies (clustered by illness perception measure)

Study IP measure	Summary of findings	Summary of relationships between dimensions of illness perceptions and outcomes Distress	QOL	Functioning	Psychosis symptoms	Change over time
Birchwood 2005 (Study 1) PBIQ: subscale scores	Those who went on to develop post psychotic depression at 3 month follow up had attributed their cause of their psychosis to the self (F = 4.3*), perceived greater loss (F = 4.9*), humiliation (F = 4.0, p = 0.05) and as having less control (F = 3.5, p = 0.07).	Control Loss Humiliation Self as illness				
Iqbal 2000 *(Longitudinal analysis)* PBIQ: subscale scores	Predicting depression at 12 month follow up: At pre PPD stage (when neither group was depressed), the PPD group was significantly more likely to than the non-PPD group to perceive self as illness (F = 4.3*), lower control (F = 3.5, p = 0.07), greater loss (F = 4.9*) and humiliation (F = 4.0, p = 0.05), no differences between groups for shame. Predicting relapse: no differences in illness perceptions at pre-PPD stage between those later relapsed and those who did not.	Control Loss Humiliation Self as illness			X	
Rooke 1998 *(Longitudinal analysis)* PBIQ: subscale scores	There was stability in appraisals of control (r = 0.42**), loss (r = 0.67**) and self as illness r = 0.55**) but not for shame or humiliation at 30 month follow up. Depression at follow up was predicted by baseline depression and perceptions of control over psychosis (β = 0.39***) and change in control (β = 0.39***) during follow-up period. Compulsory admission to hospital and baseline perceptions of control predicted a decrease in perception of control over illness.	Control			Control	*Stable:* Control Loss Cause *Not stable:* Shame Humiliation Control- change predicted by compulsory hospital admission
Lobban 2004 *(Longitudinal analysis)* IPQS: subscale scores	Higher perception of negative consequences at baseline predicted higher levels of depression (sB = 2.2*), poorer QOL (sB = -3.6***), and lower satisfaction with mental health (sB = -3.2**) at 6 months follow up.	Consequences	Consequences			

Study IP measure	Summary of findings	Summary of relationships between dimensions of illness perceptions and outcomes Distress	QOL	Functioning	Psychosis symptoms	Change over time
Lobban 2005 *(Test-retest reliability analysis)* IPQS: subscale scores	Test-retest reliability showed stability over 2 weeks for all subscales (range r = 0.57 to 0.95) except personal blame. Coherence and treatment control showed a slight increase over 2 weeks (p = 0.041 and 0.046, respectively). Test-retest reliability showed stability over 6 months for all subscales (range r = 0.31 to 0.73**) except personal blame.					*Stable:* Identity Cause Timeline chronic Timeline cyclical Consequences Personal control Treatment control (slight ↑ 2 weeks) Coherence (slight ↑ 2 weeks) Emotional response *Not stable:* Personal blame
Stainsby 2010 *(longitudinal analysis)* IPQS: subscale scores	Perceptions of fewer negative consequences (r = -0.59, p = 0.001), a more coherent understanding (r = -0.45, p = 0.019), less emotional distress (r = -0.52, p = 0.005) and more symptoms (r = -0.47, p = 0.014) were correlated with better QoL at 2 year follow-up. None of these associations were independently significant in regression analyses, although coherence approached significance, model overall was significant (Adjusted R2 = .34, $F_{5,21}$ = 3.63, p = 0.016). No associations were found between illness perceptions at baseline and impairment in life skills at follow-up.		Consequences[C] Coherence[C] Emotional[C] Symptoms[C]	X		
Lobban 2013 *(longitudinal analysis)* BIPQ: item scores with additional items	Beliefs about severity of consequences (OR = 1.24, 95% CI 1.01,1.52) and personal effort (OR = 0.82, 95% CI 0.67,1.02) at baseline affected the likelihood of greater fluctuations of depressed mood over 24 weeks. Greater perceived negative consequences was associated with lower social and occupational functioning (r = -0.26, p = 0.02), being unable to work (t = -2.36, p = 0.02) and a higher number of relapses in the previous 3 years (r = -0.25, p = 0.02). Beliefs of more severe consequences (OR = 1.38, 95% CI 1.07,1.77), higher identification of symptoms (OR = 0.75, 95% CI 0.59,0.95) and more concern (OR = 1.30, 95% CI 1.04,1.61) was associated with shorter time to relapse. Illness perception items showed moderate to substantial stability over time (range B = 0.31-0.72).	Consequences Personal effort		Consequences	Consequences Identity Concern	*Stable:* Identity Timeline chronic Consequences Personal control Treatment control Coherence Emotional response Concern Personal effort Cause internal Personal blame

Study IP measure	Summary of findings	Summary of relationships between dimensions of illness perceptions and outcomes Distress	QOL	Functioning	Psychosis symptoms	Change over time
Berk 2013 (longitudinal analysis) ICS: total score	Worse depression symptoms at baseline predicted more negative illness perceptions at 24 months follow up ($p = 0.015$).	Total score				
McCabe 2004 SEMI	Responses to questions about concept, causes and treatment preference and hope for treatment results were not consistent at 12 months follow up. Perceived severity of illness and a chronic timeline were more stable over time. Answers at follow up were most consistent to the question "Is there anything you have or have not done to cause your illness?"					*Stable:* Severity Timeline chronic Causes: attribution to self (1 question) *Not stable:* Concept Treatment preference Causes (overall)

Key: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; [C] = effect found in correlation analysis; [R] = effect found in regression analysis; [M] = effect found in mediation analysis; CI = confidence intervals; OR = odds ratio;

Table 1.4 Findings from RCTs and Intervention studies (clustered by illness perception measure)

Study IP measure	Summary of findings	Summary of relationships between dimensions of illness perceptions and outcomes			
		Functioning	Psychosis symptoms	Engagement	Change during intervention
Drury 2000 PBIQ: subscale scores	CBTp group reported significantly increased control over illness ($F_{1,28}$ = 8.64, p = 0.007) but no difference in humiliation at 5-year FU compared to control group. No significant change in illness perceptions not targeted by CBTp (loss, shame or self as illness subscales). In participants who only relapsed once or not at all, CBTp group followed same pattern with significant increase for control $F_{1,18}$ = 7.73, p = 0.012) and no significant change for other dimensions.				↑ Control X Loss X Shame X Humiliation X Self as illness
Gumley 2006 PBIQ: subscale scores	At 12 months, those who relapsed showed greater decrease in control over illness (β = -1.3, p = 0.02) and increase in self as illness (β = -1.0, p = 0.03) compared to those who did not, controlling for baseline covariates. Those who received CBTp showed greater improvement in perceptions of loss (β = -0.8, p = 0.02), adjusted for baseline covariates. CBTp was not associated with improvements in perceived control, shame, humiliation and self as illness.		Control Self as illness		↓ Loss X Control X Shame X Humiliation X Self as illness
Freeman 2013 MIPQ: 5 subscales	There was no difference between groups in perceived consequences at baseline. Those who did not take up therapy perceived a shorter timeline compared to the partial therapy (p = 0.043) and full therapy (p = 0.007) groups. Those who took up partial therapy had perceptions of less cure/control than the no therapy group (p = 0.012) and the full therapy group (p = 0.007). Take up of therapy was not predicted by severity of symptoms. Those who took up full therapy (CBTp) were more likely to attribute the cause of their problems to their personality compared to those who took up partial (X^2 = 5.89, p = 0.015) or no therapy (X^2 = 3.88, p = 0.049). Those in the full therapy group were more likely to perceive state of mind as a cause compared to those who took up partial therapy (X^2 = 8.83, p = 0.003) but not more than the no therapy (X^2 = 2.23, p =0.135). Those in the partial therapy group were more likely to perceive pollution as a cause compared to those who took up full (X^2 = 5.62, p = 0.018) and no therapy (X^2 = 4.02, p = 0.045). Together, state of mind, personality, pollution, cure/control and timeline predicted uptake of therapy correctly for 58.1% of cases. Prediction of full therapy (64.9%) was higher than for partial (54.8%) or no therapy (50.0%).			Cure/control Causes Timeline chronic	
Marcus 2014 *(intervention analysis)* MIPQ: 3 subscales	Higher perception of Cure/Control at baseline predicted lower levels of paranoia following therapy (β = 0.04, p = 0.03) controlling for baseline distress, conviction and belief inflexibility. Cure/Control x therapy allocation interaction predicted paranoia (β = -1.0, p = 0.04) controlling for allocation, Cure/Control and baseline paranoia.		Cure-Control		

Study IP measure	Summary of findings	Summary of relationships between dimensions of illness perceptions and outcomes			
		Functioning	Psychosis symptoms	Engagement	Change during intervention
Etain 2018 BIPQ total score (additional BP question)	Those who completed the intervention had significantly more adaptive/positive illness perceptions at baseline compared to those that dropped out ($t = 2.76$, $p = 0.006$). Illness perceptions significantly improved (became more positive) in those that completed the intervention ($t = -0.37$, $p = 0.0003$). Mediation analysis: only change in illness perception was associated with change in social functioning ($\beta = 0.13$, $p = 0.03$), with no contribution (direct or indirect) of changes in adherence to medication or knowledge in BD on change in social functioning.	Total score		Total score	↑ Total score: became more positive Change in illness perceptions associated with change in social functioning
Proudfoot 2012 BIPQ: Personal Control and Understanding items	Significant increase in perceptions of control from pre- to post-treatment across all groups, but not in understanding. Groups did not differ in the amount of change from pre to post, 3 months or 6 months-for either perceptions of control or understanding. Baseline control and understanding scores predicted change during treatment from pre v post ($F = 0.86$**; $F = 0.75$**, respectively), pre v 3 months ($F = 0.73$**; $F = 0.76$**, respectively) and pre v 6 months ($F = 0.87$**; $F = 0.77$**, respectively). The subset of participants who completed all eight workbooks revealed the same pattern of results.				↑ Control X Understanding Baseline control & understanding predicted change
Awan et al. (2017) SEMI	Most commonly reported concept at baseline was mental illness, consistent between groups ($p > 0.05$). At follow up, intervention group reported higher concept of psychosis ($p < 0.001$) and less concept of physical illness ($p = 0.020$) compared to the TAU group. Most common attributed causes at baseline were stress, supernatural and spiritual. At baseline, intervention group reported more stress ($p = 0.008$) and less supernatural ($p = 0.028$) causal explanations compared to TAU group. At follow up, intervention group reported more biological ($p < 0.001$) and stress ($p < 0.001$) causal explanations and less supernatural causal explanations ($p < 0.001$) compared to TAU group. No significant differences in treatment choice. No difference between groups in perceived severity at baseline. At follow up, intervention group reported less perceptions of illness as "not serious" ($p = 0.014$) and more perceptions of illness as "very serious" ($p = 0.003$) compared to TAU group.				↑ Concept ↑ Severity Causes: ↑ Biological X Treatment choice

Key: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; X = relationship investigated but not statistically significant ; C = relationship significant in correlation analysis; R = relationship significant in regression analysis; M = relationship significant in mediation analysis; ^strongest effect size; QoL = Quality of life; PPD = post-psychotic depression; BD = bipolar disorder

Table 1.5 Quality assessment of included studies (see appendix D for rating information)

Study ID	Overall rating	A) Selection bias	B) Study Design	C) Confounders	E) Data collection methods	F) Withdrawals and drop-outs
Acosta 2013	Weak	Moderate	Moderate	Weak	Strong	Weak
Awan 2017	Strong	Moderate	Strong	Strong	Strong	Moderate
Berk 2013	Weak	Moderate	Weak	Weak	Strong	Moderate
Birchwood 1993	Moderate	Moderate	Weak	Strong	Strong	Moderate
Birchwood 2005 Study 1	Weak	Moderate	Moderate	Weak	Strong	Weak
Birchwood 2005 Study 3	Weak	Moderate	Weak	Weak	Strong	Weak
Broadbent 2008	Weak	Weak	Weak	Weak	Strong	Moderate
Cavelti 2012a	Weak	Moderate	Weak	Weak	Strong	Moderate
Cavelti 2012b	Weak	Moderate	Weak	Weak	Strong	Moderate
Drury 2008	Moderate	Moderate	Strong	Strong	Weak	Moderate
Etain 2018	Weak	Weak	Moderate	Strong	Weak	Weak
Fialko 2006	Moderate	Moderate	Weak	Strong	Strong	Moderate
Freeman 2013	Strong	Moderate	Moderate	Strong	Strong	Moderate
Gomez-de-Regil 2014	Moderate	Moderate	Weak	Strong	Strong	Moderate
Gomez-de-Regil 2015	Moderate	Moderate	Weak	Strong	Strong	Moderate
Gumley 2006	Strong	Moderate	Strong	Strong	Strong	Strong
Iqbal 2000	Moderate	Moderate	Moderate	Weak	Strong	Moderate
Karatzias 2007	Moderate	Moderate	Weak	Strong	Strong	Moderate
Lobban 2004	Strong	Moderate	Moderate	Strong	Strong	Strong
Lobban 2005	Weak	Moderate	Weak	Weak	Strong	Strong
Lobban 2013	Strong	Moderate	Moderate	Strong	Strong	Strong
Maguire 2016	Weak	Moderate	Weak	Strong	Weak	Moderate
Marcus 2014	Moderate	Moderate	Moderate	Strong	Strong	Weak
McCabe 2004	Weak	Moderate	Moderate	Weak	Strong	Weak
McGlashan 1981	Weak	Moderate	Weak	Weak	Strong	Moderate
Moriarty 2012	Moderate	Moderate	Weak	Strong	Strong	Moderate
Proudfoot 2012	Moderate	Weak	Strong	Strong	Strong	Moderate
Rooke 1998	Moderate	Moderate	Moderate	Weak	Strong	Strong
Shah 2009	Weak	Weak	Weak	Weak	Strong	Moderate
Stainsby 2010	Moderate	Weak	Moderate	Strong	Strong	Moderate
Theodore 2012	Weak	Weak	Weak	Strong	Strong	Moderate
Watson 2006	Weak	Moderate	Weak	Weak	Strong	Moderate
White 2007	Weak	Moderate	Weak	Weak	Strong	Moderate

Relationships between illness perceptions and outcomes

Findings from each study are reported in separate tables according to type of analysis (Tables 1.2-1.4). Within each table, studies are clustered by illness perception measure and findings are separated by outcomes of interest. Findings are qualitatively synthesised below according to outcome of interest and type of analysis.

Distress outcomes

Twenty studies investigated the relationship between illness perceptions and psychological distress outcomes.

Cross sectional analyses

Fifteen studies included cross-sectional analyses investigating the relationship between illness perceptions and distress outcomes. Eight of these analyses were from longitudinal or intervention studies e.g. baseline data. The direction of the association was consistent, all studies found an association between more positive or adaptive illness perceptions and lower levels of anxiety, depression or affective comorbid conditions, hopelessness, and suicidal ideation.

Perceptions of control

Perceptions of control was the most common illness perception dimension associated with distress outcomes, found in all thirteen cross sectional analyses that assessed it.

Perceptions of having more personal control over illness were correlated with lower levels of depression in eight studies (Acosta, Aguilar, Cejas, & Gracia, 2013; Birchwood, Iqbal, & Upthegrove, 2005; Birchwood, Mason, MacMillan, & Healy, 1993; Cavelti et al., 2012b; Iqbal, Birchwood, Chadwick, & Trower, 2000; Lobban et al., 2013; White, McCleery, Gumley, & Mulholland, 2007), and lower levels of hopelessness in two studies (Acosta et al., 2013; White et al., 2007). The association between control and depression was strong compared to other illness perceptions in one study (Birchwood et al., 1993). Perceptions of higher personal control were independently associated with the absence of both anxiety or affect disorders in one study (Karatzias, Gumley, Power, & O'Grady, 2007), Perceptions of more personal effort to get well was correlated with lower levels of depression (Lobban et al., 2013).

Perceptions that treatment could be helpful (treatment control) were correlated with lower levels of depression in five studies (Cavelti, Beck, Kvrgic, Kossowsky, & Vauth, 2012a; Cavelti et al., 2012b; Lobban et al., 2004; Lobban, Barrowclough, & Jones, 2005; Theodore et al., 2012) and with lower levels of anxiety in two studies (Lobban et al., 2004, 2005; Theodore et al., 2012).

Perceptions of more control and curability (assessed using a subscale) was associated with lower levels of depression and anxiety in one study (Watson et al., 2006) and with less suicidal ideation in one study (Fialko et al., 2006).

Perceptions of consequences/loss of autonomy

Eleven out of thirteen studies found associations between perceptions of consequences or loss and distress outcomes in cross-sectional analyses. Perceptions of higher loss of autonomy were associated with higher levels of depression in five studies (Acosta et al., 2013; Birchwood et al., 2005; Birchwood et al., 1993; Iqbal et al., 2000; White et al., 2007), and with higher levels of hopelessness in two studies (Acosta et al., 2013; White et al., 2007). One of these studies found these associations independent of other dimensions of illness perceptions (Acosta et al., 2013). Perceptions of more severe consequences were associated with higher levels of depression in five studies (Cavelti et al., 2012a; Cavelti et al., 2012b; Lobban et al., 2004, 2005; Watson et al., 2006), with worse anxiety in three studies (Lobban et al., 2004, 2005; Watson et al., 2006), more suicidal ideation in one study (Fialko et al., 2006). One of these studies found the association with depression as independent of other IPQ dimensions (Watson et al., 2006).

Perceptions of illness timeline

Perceptions of timeline were associated with distress outcomes in six out of seven studies. Perceptions of a more chronic timeline were associated with higher levels of depression in five studies (Cavelti et al., 2012a; Cavelti et al., 2012b; Lobban et al., 2004, 2005; Watson et al., 2006) with higher levels of anxiety in three studies (Lobban et al., 2004, 2005; Watson et al., 2006) and with more suicidal ideation in one study (Fialko et al., 2006). One study found this as an independent association (Watson et al., 2006). Perceptions of a cyclical timeline was associated with higher levels of depression in two studies (Cavelti et al., 2012b; Lobban et al., 2004) and with higher levels of anxiety in two studies (Lobban et al., 2004, 2005).

Perceptions of a coherent understanding of illness

Perceptions of coherence were associated with distress outcomes in three out of seven studies. Perceptions of a more coherent understanding of illness correlated with lower levels of depression in three studies (Cavelti et al., 2012b; Lobban et al., 2004, 2005). One of these studies found this association independent of other illness perception dimensions and positive and negative psychosis symptoms (Lobban et al., 2004).

Identification of symptoms

Identity of symptoms was associated with distress outcomes in four out of six studies. Higher identification of symptoms correlated with higher levels of depression in four studies (Cavelti et al., 2012b; Lobban et

al., 2004, 2005; Watson et al., 2006), higher levels of anxiety in three studies (Lobban et al., 2004, 2005; Watson et al., 2006). Two of these studies found this as an independent association with anxiety (Lobban et al., 2004; Watson et al., 2006) and one with depression (Watson et al., 2006).

Causal attributions

Causal attributions were correlated with distress outcomes in three studies, although only a small number of studies assessed this relationship as it was frequently collected as categorical data as therefore could not be meaningfully analysed. Attribution of symptoms to mental health problems correlated with higher levels of anxiety in two studies (Lobban et al., 2004, 2005). Attributing cause to state of mind correlated with higher levels of anxiety in one study (Watson et al., 2006). Attribution to medication side effects or other factors correlated with lower levels of depression in one study (Lobban et al., 2005). Attribution to other factors also correlated with lower levels of anxiety (Lobban et al., 2005).

Emotional representations

Emotional representations were associated with distress outcomes in three out of six studies. Perceptions of a more negative emotional response correlated with higher levels of depression in three studies (Cavelti et al., 2012b; Lobban et al., 2005) and with higher levels of anxiety in one study (Lobban et al., 2005). Perceptions of more negative emotional representations (composite subscale including emotional response and concern items) was associated with higher levels of depression and anxiety in the only study that assessed illness perceptions in this way (Gómez-de-Regil, 2015).

Cognitive representations

More positive cognitive representations were associated with lower levels of depression and anxiety in the one study that used a composite subscale (Gómez-de-Regil, 2015).

Illness perceptions dimensions assessed only by the PBIQ: Humiliation, shame and self as illness

Other dimensions of illness perceptions assessed by the PBIQ were associated with distress outcomes in five out of the six studies. Higher levels of humiliation were associated with higher levels of depression in three studies (Acosta et al., 2013; Birchwood et al., 1993; Iqbal et al., 2000; White et al., 2007) and hopelessness in two studies (Acosta et al., 2013; White et al., 2007), one of these studies found this as an independent association (Acosta et al., 2013). Perceptions of more shame were associated with higher levels of depression in three studies (Birchwood et al., 2005; Birchwood et al., 1993; Iqbal et al., 2000) and independently with higher levels of hopelessness in one study (White et al., 2007). Perceptions of self as illness were associated with higher levels of depression in three studies (Birchwood et al., 1993; Iqbal et al., 2000; White et al., 2007) and with higher levels of hopelessness in two studies (Acosta et al., 2013; White et al., 2007).

Overall illness perceptions

Two studies investigated associations between overall illness perceptions (i.e. total scores) and distress outcomes. One study found that more negative overall illness perceptions (PBIQ total score) were associated with high levels of depression and anxiety (Acosta et al., 2013). Another study also found that more negative overall illness perceptions (ICS total score) were associated with worse depression (Berk et al., 2013).

Longitudinal studies

Five studies included longitudinal analyses investigating the relationship between illness perceptions and distress, specifically depression. All studies found an association between more positive or adaptive illness perceptions and lower levels of depression.

Perceptions of control

Three out of four studies that assessed individual dimensions of illness perceptions found that baseline perceptions of less control over illness predicted higher levels of depression at follow up after 3 months (Birchwood et al., 2005), 12 months (Iqbal et al., 2000) and 30 months (Rooke & Birchwood, 1998). Rooke and Birchwood (1998) also found that change in perception of control predicted depression at follow up.

Other illness perception dimensions

Longitudinal associations between illness perceptions other than control were assessed in relation to depression in five studies. Perceptions of worse consequences predicted higher levels of depression after 6 months in one study (Lobban et al., 2004) and increased likelihood of greater fluctuations in depressed mood in bipolar over 24 weeks in another study (Lobban et al., 2013) but no association was found in the other study after 30 months (Rooke & Birchwood, 1998). Lobban et al. (2013) found that perceptions of personal effort to get well predicted decreased likelihood of fluctuations in depressed mood in bipolar over 24 weeks, this association was not assessed in other studies. Two out of three studies that used the PBIQ found that perceptions of more loss, humiliation and self as illness predicted higher levels of depression at follow up after 3 months (Birchwood et al., 2005) and 12 months (Iqbal et al., 2000).

Overall illness perceptions

One study investigated the relationship in the other direction to find out whether depression predicted illness perceptions (total score) at follow up and found that worse depression symptoms predicted more negative overall illness perceptions at 24 month follow up (Berk et al., 2013).

Intervention studies

No intervention studies investigated the relationship between illness perceptions with levels of distress.

Wellbeing and quality of life outcomes

Ten studies investigated the relationship between illness perceptions and wellbeing or quality of life outcomes.

Cross sectional analyses

Eight studies included cross-sectional analyses investigating the relationship between illness perceptions quality of life or wellbeing outcomes. The direction of the association was consistent, all studies found an association between more positive or adaptive illness perceptions and higher subjective wellbeing, quality of life, satisfaction with mental health or self-rated mental health.

Perceptions of control

Four out of five studies found cross-sectional associations with perceptions of control with quality of life or wellbeing outcomes. Perceptions of having less personal control over illness were associated with higher satisfaction with mental health and independently with lower quality of life in one study (Lobban et al., 2004), and strongly and independently with 'poor self-rated mental health in one study (Maguire, Reay, & Raphael, 2016). Perceptions that treatment could be helpful (treatment control) were associated with higher quality of life in two studies (Lobban et al., 2004; Theodore et al., 2012), with higher satisfaction with mental health in one study (Lobban et al., 2004), and with better subjective wellbeing while under antipsychotic treatment in one study (Cavelti et al., 2012b). The associations with treatment control were all independent except in one study (Lobban et al., 2004).

Perceptions of consequences

Five out of five studies found associations between perceptions of consequences and quality of life outcomes. Perceptions of more severe consequences were associated with poorer quality of life in three studies (Lobban et al., 2004; Stainsby, Sapochnik, Bledin, & Mason, 2010; Theodore et al., 2012), independently 'poor' self-rated mental health in one study (Maguire et al., 2016), poorer subjective wellbeing while under antipsychotic treatment in one study as (Cavelti et al., 2012b), and satisfaction with mental health in one study (Lobban et al., 2004). All of these associations were found to be independent, except for quality of life in two studies (Lobban et al., 2004; Theodore et al., 2012), the latter of which approached significance.

Perceptions of illness timeline

Three out of five studies found associations between perceptions of timeline and quality of life outcomes. Perceptions of a more chronic timeline were associated with and worse subjective wellbeing while under antipsychotic treatment in one study (Cavelti et al., 2012b), poorer quality of life, and with satisfaction with mental health in one study (Lobban et al., 2004). An independent association was found between a

shorter timeline and 'very good' self-rated mental health in one study (Maguire et al., 2016). Perceptions of a cyclical timeline was associated with worse subjective wellbeing while under antipsychotic treatment in one study (Cavelti et al., 2012b), poorer quality of life and lower satisfaction with mental health in one study (Lobban et al., 2004). The absence of a negative attitude of the future in relation to illness was associated with more fullness of life in one study, which appeared to be more important than a positive attitude (McGlashan & Carpenter, 1981).

Perceptions of a coherent understanding of illness

Four out of five studies found associations between coherence and quality of life outcomes. Perceptions of a less coherent understanding of illness correlated with poorer quality of life in two studies (Lobban et al., 2004; Stainsby et al., 2010), lower satisfaction with mental health in one study (Lobban et al., 2004), independently with 'poor' self-rated mental health in one study (Maguire et al., 2016) and independently with lower subjective wellbeing while under antipsychotic treatment in one study (Cavelti et al., 2012b). Additionally, higher comprehensibility was associated with better quality of life in the one study that assessed it using this composite subscale (Gómez-de-Regil, Kwapil, & Barrantes-Vidal, 2014).

Identification of symptoms

Identification of symptoms was associated with quality of life outcomes in two out of five studies. More identification of symptoms was associated with poorer quality of life and satisfaction with mental health in one study (Lobban et al., 2004), with poorer subjective wellbeing while under antipsychotic treatment in one study (Cavelti et al., 2012b), and independently with poorer self-rated mental health in one study (Maguire et al., 2016).

Causal attributions

Causal attributions were associated with quality of life outcomes in two studies. Attribution of symptoms to mental health problems correlated with poorer subjective wellbeing while under antipsychotic treatment in one study (Cavelti et al., 2012b). Attribution to other factors was independently associated with higher satisfaction with mental health in one study (Lobban et al., 2004).

Emotional representations

Perceptions of emotional response were associated with quality of life outcomes in four out of six studies. Perceptions of a more negative emotional response correlated with worse subjective wellbeing in one study (Cavelti et al., 2012b), poorer quality of life in one study (Theodore et al., 2012), worse self-rated health in one study (Maguire et al., 2016). Perceptions of more a negative emotional response and more concern (composite subscale) was associated poorer quality of life in one study (Gómez-de-Regil et al., 2014). More concern with illness was associated with worse self-rated health in one study (Maguire et al., 2016).

Cognitive representations

More positive cognitive representations (composite subscale) fully mediated the association between residual symptoms and better quality of life in the one study that assessed illness perceptions in this way (Gómez-de-Regil et al., 2014).

Total scores

Both studies that investigated overall illness perceptions found an association with quality of life or wellbeing outcomes. One study found that more negative overall illness perceptions (ICS total score) were associated with poorer quality of life and lower subjective wellbeing (Berk et al., 2013). The other study found negative attitudes towards illness were associated with lower fullness of life (McGlashan & Carpenter, 1981).

Longitudinal studies

Both studies which included longitudinal analyses found a relationship between baseline illness perceptions and quality of life or wellbeing outcomes at follow up. Perceptions of worse consequences predicted poorer quality of life and less satisfaction with mental health after six months (Lobban et al., 2004), poorer quality of life after two years (Stainsby et al., 2010). Additionally, Stainsby et al. (2010) found that perceptions of a less coherent understanding, more emotional distress and more symptoms predicted poorer quality of life at follow-up after two years.

Intervention studies

No intervention studies investigated the relationship between illness perceptions with wellbeing and quality of life.

Functioning

Nine studies investigated the relationship between illness perceptions and functioning outcomes.

Cross sectional relationships

Six studies included cross-sectional analyses investigating the relationship between illness perceptions and functioning. Two studies found no significant association with life skills (Stainsby et al., 2010) or activity level (Moriarty, Jolley, Callanan, & Garety, 2012). Four studies found that more negative illness perceptions were associated with poorer functioning. Two of these studies found that more positive illness perceptions total score was associated with better functional health (Berk et al., 2013; McGlashan & Carpenter, 1981). Specifically, the latter study found that the absence of a negative attitude of the future appeared to be more important than a positive attitude. Perceptions of higher personal control were associated with better functioning in two studies (Broadbent, Kydd, Sanders, & Vanderpyl, 2008; Lobban et al., 2004). Less

identification of symptoms was associated with better global functioning in one study (Broadbent et al., 2008). One study found that attributing cause of symptoms to medication side effects, less chronic timeline, less severe consequences, more personal control, more belief in treatment being effective and more coherent understanding were associated with better global functioning (Lobban et al., 2004), of which causal attribution and consequences were independent associations.

Longitudinal studies

Two longitudinal studies assessed the relationship between illness perceptions and functioning. One study did not find any significant association between illness perceptions at baseline and life skills at 2-year follow-up (Stainsby et al., 2010). The other study found that greater perceived negative consequences predicted lower social and occupational functioning after 24 weeks (Lobban et al., 2013).

Intervention studies

One intervention study assessed the relationship between illness perceptions and functioning and found that change in illness perceptions (total score) had a direct effect on change in social functioning, mediating any direct or indirect effects of adherence to medication or knowledge of bipolar (Etain et al., 2018).

Positive symptoms

Fifteen studies investigated the relationship between illness perceptions and positive symptom outcomes.

Cross sectional relationships

Ten studies investigated cross-sectional relationships between illness perceptions and positive symptoms. All studies found significant associations, however the dimensions of illness perceptions varied between studies.

Perceptions of control

Six studies found associations between various perceptions of having more control and less severe psychosis symptoms. The specific types of control for which significant associations were found included, control over illness in two studies (Rooke & Birchwood, 1998; White et al., 2007), cure/control combined as a subscale in three studies (Fialko et al., 2006; Marcus et al., 2014; Watson et al., 2006), perception of personal control and perception that treatment is likely to be helpful in one study (Cavelti et al., 2012b), of which treatment control was an independent association. There was one exception in the direction of the association, whereby perceptions of having more control over illness were associated with the presence of grandiose and religious delusions (Rooke & Birchwood, 1998).

Other dimensions of illness perception

Two studies found associations between perceptions of a longer and cyclical timeline with worse psychosis symptoms (Fialko et al., 2006; Lobban et al., 2005). One study found an association between a more negative attitude about the future of illness and more severe psychosis symptoms (McGlashan & Carpenter, 1981), a positive attitude toward the future seemed less important than the absence of a negative attitude.

One study found that attribution of symptoms to mental health problems correlated with worse severity of positive symptoms. Two studies found an association between higher identity of symptoms as being part of illness (identity subscale) and more severe positive symptoms (Lobban et al., 2005; Watson et al., 2006). Two studies found associations between worse perceived consequences of illness and more severe symptoms (Fialko et al., 2006; Lobban et al., 2005). Two studies found associations between more negative emotional response/representations and worse symptoms (Gómez-de-Regil, 2015; Lobban et al., 2005). Two studies found associations between more negative cognitive representations and worse symptoms (Gómez-de-Regil, 2015). One study found an association between perceptions of more loss, shame, self as illness and humiliation with worse symptoms (White et al., 2007). One study found an association between more negative total illness perception score and worse overall bipolar symptoms (Berk et al., 2013).

Longitudinal studies

Three studies investigated longitudinal relationships between illness perceptions and psychosis symptoms. One study found no significant relationship between illness perceptions between those who later relapsed and those who did not (Iqbal et al., 2000). The second study found that perceptions of more severe consequences, higher identification of symptoms and concern at baseline were associated with shorter time to relapse of psychosis symptoms during the following 24 weeks (Lobban et al., 2013). The third study found that compulsory admission to hospital and baseline perceptions of control predicted a decrease in perception of control over illness (Rooke & Birchwood, 1998).

Intervention studies

Two intervention studies investigated the relationship between illness perceptions and psychosis symptoms. Although different illness perception measures were used, both studies found that higher perceptions of control were associated with worse symptom outcomes. One study found that lower perceptions of control/cure at baseline were associated with higher levels of paranoia following therapy (Marcus et al., 2014). The other study found that those who had relapsed reported greater decreases in control over illness compared to those who did not (Gumley et al., 2006). Additionally, this study found that those who relapsed reported a greater increase in perceptions of self as illness (Gumley et al., 2006).

Engagement

Three studies investigated the relationship between illness perceptions and engagement outcomes.

Cross sectional relationships

Only one cross-sectional study investigated the relationship between illness perceptions and engagement (Shah, Hull, & Riley, 2009) and found that better self-reported engagement (i.e. actively working on mental health problems) was associated with perceptions of a chronic and cyclical timeline and higher treatability.

Longitudinal relationships

No longitudinal studies investigated the relationship between illness perceptions and engagement.

Intervention studies

Two intervention studies investigated the relationship between illness perceptions and engagement. Freeman et al. (2013) assessed the relationship in CBTp and found that those who took up full therapy were more likely to attribute the cause of their problems to their personality and state of mind and had perceptions of a longer timeline compared to those who took up partial for no therapy. There were non-linear relationships with engagement, whereby perceptions of less cure/control and causal attributions of pollution were associated with partial take up of therapy, compared to none or full therapy. Etain et al. (2018) found that those who completed the three month psychoeducation for bipolar intervention more adaptive/positive overall illness perceptions (total score) at baseline compared to drop out.

Change in illness perceptions over time

Ten studies investigated change in illness perceptions of over time as an outcome.

Longitudinal studies

Five longitudinal studies investigated change in illness perceptions over time. Lobban et al. (2013) was the only study which found stability for all illness perception dimensions over 24 weeks. Rooke and Birchwood (1998) found stability in perceptions of control, loss and self as illness but not for shame or humiliation over 30 months. Lobban et al. (2005) found stability for all subscales except personal blame, over six months. Over two weeks, a similar pattern was found except for slight increases in treatment control and coherence. McCabe and Priebe (2004) found stability in participants' answers to questions related to perceptions of severity of illness, chronic timeline and causal attributions to self after one year. Answers related to perceptions of illness concept, treatment preference and perceptions of other causes were not consistent after one year. Rooke and Birchwood (1998) found that compulsory admission to hospital and baseline perceptions of control predicted a decrease in perception of control over illness.

Intervention studies

Five studies investigated change in illness perceptions during psychological or psychosocial interventions.

CBTp

Two studies investigated the role of illness perceptions in CBTp. One study found that overall the CBT group reported significantly increased control over illness but no difference in humiliation at 5-year follow up compared to the control group who received recreational activities and support (Drury, Birchwood, & Cochrane, 2000). No significant changes in illness perceptions were found for those not targeted by CBT i.e. loss, shame or self as illness subscales. Another study found that those who received CBT showed greater improvement in perceptions of loss, adjusted for baseline covariates at 12 month follow up. However, CBT was not associated with improvements in perceived control, shame, humiliation and self as illness 12 month follow up (Gumley et al., 2006). Additionally, those who had relapsed during the 12 months showed greater decrease in control over illness and increase in self as illness compared to those who did not, controlling for baseline covariates.

Psychoeducation interventions

Three studies investigated the role of illness perceptions in psychoeducation interventions. One study assessed differences in illness perceptions between a group who received a three month psychoeducation intervention about schizophrenia and a treatment as usual control group (Awan, Jehangir, Irfan, Naeem, & Farooq, 2017). Findings related to the impact of the intervention on illness perceptions need to be interpreted with caution the due to baseline differences between groups and that tests of differences were only carried out between groups at baseline and post-intervention, with no analysis over time. At follow up, the intervention group reported higher concept of psychosis and less concept of physical illness compared to the TAU group. At follow up, the intervention group reported more biological and stress causal explanations and less supernatural causal explanations compared to TAU group. However, the differences between groups in stress and supernatural causal explanations were present at baseline. At follow up, the intervention group reported more perceptions of illness as "very serious" compared to TAU group, after no differences between groups at baseline.

Two studies investigated the role of illness in perceptions psychoeducation interventions about bipolar. One study found improvements in overall illness perceptions, whereby they became more positive after a three month psychoeducation intervention about bipolar (Etain et al., 2018). An online psychoeducation intervention (with or with peer support) about bipolar found increased perceptions of control but no change in perceptions of understanding at 6 months follow up (Proudfoot et al., 2012). This effect was also found for the control group who received only simple facts about bipolar plus daily mood monitoring. Regardless of intervention, it was found that baseline control and understanding scores predicted change in control

and understanding scores, respectively, during treatment from pre- versus post-intervention, pre-intervention versus 3 months follow up, and pre-intervention versus 6 month follow up.

DISCUSSION

Summary of main findings

This systematic review aimed to examine the empirical evidence of relationships between illness perceptions and a range of outcomes in psychosis and bipolar. Outcomes of interest included psychological distress, quality of life, functioning, positive symptoms, engagement in psychological or psychosocial interventions and change over time in illness perceptions. This review further aimed to examine the direction of these relationships. Due to the variability in the measurement of both illness perceptions and outcomes of interest, inconsistencies in findings, and the methodological quality of the included studies, it is difficult to draw many firm conclusions about the relationships between specific illness perceptions and particular outcomes. However, 32 out of the 33 studies found an association between illness perceptions and at least one outcome, and the direction of the relationships was largely consistent across these studies. The results overall indicate that more positive or adaptive illness perceptions are associated with better outcomes, with exceptions from two studies. These included one study found that perceptions of having more control over illness were associated with the presence of grandiose and religious delusions (Rooke & Birchwood, 1998). Another study which found that perceptions of a longer timeline predicted uptake of full therapy (compared to partial for no therapy) (Freeman et al., 2013) and a non-linear relationship for perceptions of more control/cure which were associated with full or no therapy compared to partial therapy. These will be discussed further in relevant sections of the discussion.

Findings of the present review need to be considered in the context of the quality of studies, which was mixed with only five were of strong quality, twelve were of moderate quality, and sixteen of the studies were of weak quality. The majority of findings were from cross-sectional analyses (twenty studies) from which causal relationships cannot be determined. Findings from a limited number of longitudinal and intervention studies (nine and seven, respectively) suggest that some dimensions of illness perceptions assessed at baseline can predict future outcomes. Only one study assessed the relationship in the other direction and found that levels of depression at baseline predicted more negative overall illness perception at 24 month follow up (Berk et al., 2013). Additionally, the findings suggest that some dimensions of illness perceptions can change over time and are amenable to change through CBT or psychoeducation interventions. This change was independently associated with change in social functioning in one study (Etain et al., 2018), but was not assessed in relation to other outcomes of interest. Overall, these links support the potential role of illness perceptions in therapeutic change, and as a possible target in

psychological therapies. A number of priorities for future research are identified and discussed. Findings are discussed in detail in the sections below.

Illness perceptions and distress outcomes

All fifteen cross-sectional analyses and all six longitudinal analyses that examined this relationship, found that more positive illness perceptions were associated with lower levels of psychological distress outcomes, which included anxiety, depression, hopelessness or suicidal ideation. No intervention studies investigated relationships with these outcomes. Relationships with distress outcomes were more commonly found with some dimensions of illness perceptions.

First, associations with perceptions of control (personal or treatment) were found in all thirteen cross sectional analyses and three out of five longitudinal analyses that assessed it. Longitudinal findings demonstrated a directional relationship where baseline perceptions of control predicted distress outcomes at three, twelve and thirty months follow up. Additionally, one study demonstrated that a reduction in perceptions of control predicted higher levels of depression at follow up (Rooke & Birchwood, 1998). Other potential directions of this relationship were not assessed. One study used an additional question to assess perceptions of personal effort to get well, which predicted decreased likelihood of greater fluctuations in depressed mood in bipolar over 24 weeks (Lobban et al., 2013).

Second, perceptions of consequences or loss of autonomy were associated with distress outcomes in eleven out of thirteen cross-sectional analyses and four out of five longitudinal analyses that assessed it. Longitudinal findings demonstrated a directional relationship where baseline perceptions of worse consequences or more loss of autonomy predicted higher levels of depression at three, six and twelve months follow up or greater fluctuation in depressed mood in bipolar over 24 weeks. Other potential directions of this relationship were not assessed.

Relationships between distress outcomes and other illness perceptions based on the SRM were only found in cross-sectional but not longitudinal analyses. Perceptions of a more chronic or cyclical timeline correlated with worse distress outcomes in six out of seven cross-sectional analyses that assessed it. Perceptions of a more coherent understanding of illness were associated with lower levels of depression in three out of seven cross-sectional analyses that assessed it. This association was found to be independent of other illness perception dimensions and positive and negative psychosis symptoms in one study (Acosta et al., 2013). Higher identification of symptoms was associated with higher levels of depression and/or anxiety in four out of six cross-sectional studies that assessed it. Causal attributions were correlated with distress outcomes in three studies, although only a small number of studies assessed this relationship as it was frequently collected as categorical data and therefore could not be incorporated into comparable analysis in a meaningful way. Attribution of symptoms to mental health problems, state of mind or other factors correlated with lower levels of anxiety and attribution to medication side effects or other factors correlated

with lower levels of depression. Perceptions of a more negative emotional response/representations correlated with higher levels of depression or anxiety in three out of six cross-sectional studies. More positive cognitive representations were associated with lower levels of depression and anxiety in the one study that used a composite subscale.

Illness perceptions not based on the SRM, assessed by the PBIQ, were associated with worse distress outcomes in five out of six cross-sectional studies that used it. Perceptions of more humiliation, shame and self as illness were associated with higher levels of depression and hopelessness. Two out of three longitudinal studies that used the PBIQ found that perceptions of more humiliation and self as illness predicted higher levels of depression at three and twelve months follow up.

Two cross-sectional studies used a total score to investigate the relationship between overall illness perceptions and distress outcomes and found that more positive illness perceptions were associated with lower levels of depression and anxiety. One longitudinal study investigated the relationship in a different direction and found that found that worse depression symptoms predicted more negative overall illness perceptions at 24 months follow up (Berk et al., 2013).

Illness perceptions and quality of life and wellbeing outcomes

All ten cross-sectional analyses and both longitudinal analyses that assessed this relationship found some associations between more positive illness perceptions dimensions and better wellbeing or quality of life outcomes, these included subjective wellbeing, quality of life, satisfaction with mental health and self-rated mental health. No intervention studies investigated relationships with these outcomes. Relationships with these outcomes were found in both cross-sectional and longitudinal studies for some dimensions of illness perceptions. Specifically, perceptions of more personal or treatment control were associated with better wellbeing or quality of life outcomes in four out of five cross sectional analyses but neither of the two longitudinal analyses that assessed it. Perceptions of worse consequences or more loss of autonomy were associated with worse wellbeing or quality of life outcomes in all five cross-sectional analyses and both longitudinal analyses that assessed it. Longitudinally, perceptions of worse consequences predicted less satisfaction with mental health after six months and poorer quality of life after six months and two years. Other potential directions of this relationship were not assessed. Perceptions of a more coherent understanding were associated with better wellbeing or quality of life outcomes in four out of five cross-sectional analyses and one of the two longitudinal analyses that assessed it. Longitudinally, a less coherent understanding predicted poorer quality of life at follow-up after two years. Perceptions of more negative emotional response/representations were associated with poorer wellbeing and quality of life outcomes in four out of six cross-sectional studies and the only longitudinal study that assessed it. Longitudinally, perceptions of a less coherent understanding, more emotional distress and more symptoms predicted poorer quality of life at follow-up after two years.

Relationships with other dimensions of illness were only found in cross-sectional analyses. Perceptions of a more chronic or cyclical timeline were associated with worse wellbeing or quality of life outcomes in three out of five cross-sectional analyses and neither longitudinal analyses that assessed it. Higher identification of symptoms was associated with worse wellbeing or quality of life outcomes in two out of five cross-sectional analyses and neither longitudinal analyses that assessed it. Causal attributions were associated with wellbeing or quality of life outcomes in two cross-sectional studies. Attribution of symptoms to mental health problems correlated with poorer subjective wellbeing while under antipsychotic treatment and attribution to other factors was independently associated with higher satisfaction with mental health. More positive cognitive representations (composite subscale) fully mediated the association between residual symptoms and better quality of life in the one cross-sectional study that assess illness perceptions in this way. Two cross-sectional studies used a total score to investigate the relationship between overall illness perceptions and distress outcomes and found that more negative illness perceptions were associated with poorer quality of life, lower subjective wellbeing and lower fullness of life.

Illness perceptions and functioning outcomes

More positive illness perceptions were associated with better functioning measured in various ways. However, only eight studies assessed this relationship with nine separate analyses and six of these were cross-sectional. The dimensions associated with functioning in cross-sectional analyses included identity, personal control, attributing cause of symptoms to medication side effects, chronic timeline, consequences, treatment control and coherence, as well as total score. No cross-sectional association was found with life skills or activity level. Longitudinal analyses from two studies found perceived negative consequences predicted lower social and occupational functioning after 24 weeks but showed no association with life skills after 2 years. One psychoeducation intervention about bipolar demonstrated improvements in total score of illness perceptions and this change predicted improvements in social functioning independent of changes in adherence to medication or knowledge of bipolar.

Illness perceptions and positive symptoms

Fifteen analyses from thirteen studies found relationships between illness perceptions and positive symptoms. Perceptions of less control (various types) was the most commonly associated dimension of illness perception with worse positive symptoms. This was found in six of out ten cross-sectional analyses and both CBTp studies. The cure/control subscale was the only illness perception dimension at baseline that predicted lower levels of paranoia after brief CBTp in one study (Marcus et al., 2014). The other CBTp study found that those who relapsed reported greater decreases in perceptions of control and increases in self as illness at 12 months follow up after CBTp, compared who those that did not (Gumley et al., 2006). Other dimensions of illness perceptions that were associated with positive symptoms in cross-sectional analysis included chronic and cyclical timeline, absence of a negative attitude about the future of

illness, attribution of symptoms to mental health problems, more negative consequences, emotional representations, cognitive representations, more loss, shame, self as illness, humiliation and more negative total illness perception score. There were mixed results from two longitudinal studies, with one finding that no dimensions of illness perceptions predicted relapse and the other finding that higher identification of symptoms and concern were associated with shorter time to relapse of psychosis symptoms. There was one exception in the direction of the association, whereby perceptions of having more control over illness were associated with the presence of grandiose and religious delusions (Rooke & Birchwood, 1998).

Illness perceptions and engagement outcomes

Only three of the included studies investigated the relationship between illness perceptions and engagement outcomes. Two assessed individual dimensions of illness perceptions and found that baseline perceptions of a longer timeline were associated with take up of full CBTp and better self-reported engagement. Perceptions of a more cyclical timeline and higher treatability (treatment control) were associated with better self-reported engagement (i.e. actively working on mental health problems). When assessed as a composite subscale, cure/control showed a non-linear relationship with partial take up of therapy, compared to none or full therapy. One study assessed causal attributions in relation to engagement in CBTp found that those who took up full therapy were more likely to attribute the cause of their problems to their personality and state of mind, compared to those who took up partial for no therapy. There were non-linear relationships for causal attributions of pollution which was associated with partial take up of the intervention, compared to none or full therapy. Completion of a psychoeducation intervention for bipolar was associated with more adaptive/positive overall illness perceptions (total score) at baseline compared to drop out.

Change of time in illness perceptions

Five longitudinal studies investigated change in dimensions of illness perceptions over time with mixed findings of stability or change over various periods of time without specific psychological interventions. The majority of studies that reported instability of illness perception dimensions over time did not specific the direction. Perceptions of personal control and consequences or loss of autonomy were stable in all three studies that assessed it over two and 24 weeks, six and 30 months. Perceptions of treatment control were stable over two and 24 weeks but showed a slight but significant increased over 6 months. Perceptions of a chronic timeline were stable in all three studies that assessed it over two and 24 weeks, six months and 12 months. Perceptions of identity and emotional response were stable over two and 24 weeks and six months in the two studies which assessed it. Perceptions of a coherent understanding were stable over two and 24 weeks but showed a slight but significant increased over 6 months. Perceptions of concern and personal effort were stable over 24 weeks. Perceptions of personal blame were stable in one study over 24 weeks but not stable over two weeks or six months in another study. Causal attributions were

stable in two studies over two weeks, six and 30 months in two studies and were not stable over 12 months in another study. Perceptions of shame or humiliation were not stable over 30 months assessed by the PBIQ. Perceptions of severity but not perceptions of concept or treatment preferences showed stability over 12 months assessed by the SEMI. Additionally, compulsory admission to hospital and baseline perceptions of control predicted a decrease in perception of control over illness.(Rooke & Birchwood, 1998).

Five studies investigated change in illness perceptions during psychological or psychosocial interventions. Perceptions of control increased during CBT in one study assessed after five year follow up (Drury et al., 2000), but not in another study at 12 month follow up (Gumley et al., 2006). Perceptions of loss were reduced in one CBT study at six months follow up but not in a second study after five year follow up. Perceptions of shame, humiliation and self as illness did not improve in either CBT study. Perceptions of control were increased after six month follow up of an online psychoeducation intervention about bipolar across all three groups (with or with peer support, and control group who received only simple facts about bipolar plus daily mood monitoring) (Proudfoot et al., 2012). However, there was no significant change in perceptions of understanding. Baseline control and understanding scores predicted change in control and understanding scores, respectively, post intervention and after three and six month follow ups. Increases in biological and stress causal explanations and more perceptions of illness as "very serious" were observed in a three-month psychoeducation intervention about schizophrenia (Awan et al., 2017). Finally, overall illness perceptions (total score) became more positive after a three month psychoeducation intervention about bipolar (Etain et al., 2018). One study investigated whether change in illness perceptions was predicted by symptoms and found that at 12 months, those who relapsed showed greater decrease in control over illness and increase in self as illness compared to those who did not, controlling for baseline covariates (Gumley et al., 2006).

Findings in the context of the broader literature

To the author's knowledge there are very limited previous systematic reviews which have examined the relationships between illness perceptions and outcomes in psychosis and bipolar. One review was identified (Baines & Wittkowski, 2013) which investigated these relationships in severe mental illness more broadly, also including eating disorders and depression (without psychotic features) but limited included studies to those which utilised measures based on the SRM. Of the six studies which included participants with psychosis or bipolar, the present review included all four studies which met the inclusion criteria. The present review provides an updated synthesis of the literature, not limited to a specific model of illness perceptions.

The limited number of studies assessing the role of illness perceptions on outcomes in CBTp may reflect the paucity of investigations into mechanisms of outcome more generally in CBTp trials. Trials investigating change and change processes as drivers of outcomes are limited, and this has been identified as a research

priority in recent NIHR funding calls and NICE guidelines (NICE, 2014). The PRP trial demonstrated a moderating effect of engagement on outcomes of psychosis symptoms and levels of distress (Dunn et al., 2012), however predictors of engagement are not well understood.

The SRM proposes that illness perceptions determine individual coping responses and health related behaviours. However, the included study which assessed coping style, found that baseline perceptions of consequences predicted quality of life, depression, and satisfaction with mental health at six month follow up, independently of coping style (Lobban et al., 2004). Additionally, another included study found that recovery style did not mediate the relationship between illness perceptions and outcomes at two year follow up. And that illness perceptions accounted to more variance in quality of life than recovery style (Stainsby et al., 2010). It was suggested that perceptions of illness maybe more important than how much an individual wants to approach or avoid thinking about it, however it was acknowledged this finding may be due to limitations in predictive power of the single scale recovery style measure. These studies suggest that the relationships between illness perceptions and outcomes may impact outcomes through broader mechanisms beyond styles of coping.

Illness perceptions may relate to cognitive models of psychosis which propose that appraisals are important in differentiating between diagnosable symptoms with a "need a care" versus benign anomalous experiences (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Morrison, 2001). Specifically, primary appraisals of anomalous experiences as personally significant and externally caused. Secondary appraisals (illness perceptions) of anomalous experiences relate to what they mean for the individual and their future. It is not known to what extent primary and secondary appraisals interact and influence each other but is worth considering when targeting illness perceptions. The findings that perceptions of having more control over illness were associated with the presence of grandiose and religious delusions (Rooke & Birchwood, 1998) highlight that the relationship between illness perceptions and grandiosity is likely to be different by nature, therefore it should be examined separately. This may also account for the finding that perceptions of a longer timeline predicted uptake of full therapy (Freeman et al., 2013) if ideas of grandiosity lead individuals to make shorter judgements of the timeline, but may also be to do with hopelessness.

Strengths and limitations of included papers

Methodological quality of included papers

The methodological quality was mixed. Sixteen of the studies were of weak quality, twelve were of moderate quality and five were of strong quality. These ratings represent the large number of cross-sectional studies which are limited in relation to the evidence they provide due to findings based on associations between variables rather than causal relationships. Lower ratings were also due to potential selection bias as studies usually recruited from a limited number of clinical services which reduces the

likelihood of representing the wider population. There was also a relatively high percentage of individuals who were approached to take part but declined to take part. This may reflect the population studied as individuals may be unwell and need to prioritise their treatment and recovery over participating in research studies. Studies were also rated lower due to not assessing or controlling for relevant confounders in analyses. The studies which were rated strong quality were largely RCTs or cohort intervention studies.

Limitations and strengths of the present review

Search strategy

Six papers were not identified in the search strategy. Papers were not identified due to the different words used to describe illness perceptions that were not covered by search terms e.g. "negative beliefs" or due to participants being described as "high users of mental health services" rather than with psychosis or bipolar terms. There may be bias due to other unidentified papers not included because they were not identified by the search terms. Only studies with adult participants were included, therefore the findings may not be applicable to young people. Although the search terms included at risk groups, none were identified for inclusion. This may be due to differences in language used as 'illness' perceptions may not be considered by researchers to be an appropriate term to describe secondary appraisals of an at-risk mental state. A further search using very much broader terms, but restricted to this population would be required to address this area of uncertainty.

Publication bias

It is recognised that studies are more likely to be published if findings demonstrate relationships between examined variables (Rothstein, Sutton, & Borenstein, 2005), leading to publication bias and potential overestimation of relationships between variables of interest. Only one out of the 33 included studies in this review did not find an association. There may be some bias in published studies which is reflected in this review. Therefore, there may be an overestimation of the relationship between illness perceptions and outcomes in psychosis and bipolar. Additionally, the six papers included after the scanning of reference lists of included studies may have inadvertently introduced bias, as although the aim was to increase inclusion of relevant studies, reference lists were checked only for already included studies.

Quality Assessment Tool

The quality assessment measure selected for this review has some limitations. The overall quality ratings are conservative, whereby only one "weak" component rating results in an overall rating of "moderate" despite multiple other "strong" component ratings. Additionally, none of the included studies were rated as "strong" for the selection bias component, which would have required between 80 to 100% of selected individuals agreed to take part. This is likely to reflect the population of individuals with psychosis and bipolar included in the review, which are typically harder to engage in clinical services, and likely also in

research studies. Samples from this population are commonly recruited from clinical services where individuals are likely to be receiving support and/or engaged in a form of treatment which may further reduce the likelihood of agreement to take part in research. Therefore, these component ratings assess the risk of selection bias, rather than the quality of the study itself. Thus, included studies which were well designed, scored lower due to the population being harder to engage. The quality assessment tool rated studies where less than 60% of selected individuals agreed to take part as "weak". In hindsight, the percentage of selected individuals required to agree to take part could have been reduced to reflect challenges in engagement of individuals with psychosis. However, lower levels of engagement in research would still increase the risk of bias.

Defining illness perceptions

There are some potential issues around defining illness perceptions. There is a risk of circularity for some dimensions in relation to some outcomes of interest. For instance, where the relationships between perceptions of consequences are assessed in relation to functioning, perceptions of consequences may simply reflect the current impact of the illness on functioning. This is particularly an issue in cross-sectional studies and highlights the need for longitudinal studies to assess whether changes in perceptions of consequences can predict functioning outcomes rather than merely reflect it. This may also be an issue in relation to affective outcomes and positive symptoms. Assessment of the construct validity of illness perception dimensions in the IPQS indicated high correlations between perceptions of more emotional representations and levels of anxiety and depression (Lobban et al., 2005). Measures of symptoms often rely on self-report and can include questions relating to perceptions of control over symptoms e.g. voices. It is important theoretically to define perceptions of control over illness as separate from control over symptoms, although in practice this may be challenging. The present review attempted to overcome this somewhat by excluding studies which only assessed perceptions of one symptom e.g. hearing voices rather than perceptions of a mental health condition. One study utilised an observer rated symptom measure and did still find this correlated with perceptions of symptom identity (Watson et al., 2006).

Perceived causes were not included in analyses of several studies due to the categorical nature of the data and difficulties with incorporating this dimension in a meaningful and comparable way. Additionally, it is difficult to ascertain what causal explanations mean to an individual, which further complicates trying to understand their relationship with outcomes. Other illness perceptions were largely studied with the assumption that the relationship is linear and consistent with outcomes across a positive to negative range. However, one study separated positive and negative perceptions in analyses and concluded that the absence of a negative attitude of the future in relation to illness was associated with outcomes, which appeared to be more important than the presence of a positive attitude (McGlashan & Carpenter, 1981). Additionally, there is ambiguity around in which direction a perception of illness if considered more positive or adaptive. For instance, perceptions of a longer timeline is considered more "negative" when scored but

it is associated with better engagement in therapy (Freeman et al., 2013), perceptions of having more control were associated with the presence of grandiose and religious delusions (Rooke & Birchwood, 1998), and perceptions of more control/cure were associated with full or no therapy compared to partial therapy. This suggests that the relationships between illness perceptions and outcomes may be complex and care should be taken with assumptions relating to linearity and direction, particularly if using composite subscales or total scores.

Measurement concerns

There was a large range of illness perception measures used across included studies. Some of this variation was due to different versions of the IPQ in modified, adapted or brief forms. Other variation came from measures developed based on different psychological models, of which there was some overlap in relation to two illness perception dimensions: control and consequences or loss. However, the SRM based measures assessed control in relation to personal and treatment control, whereas the PBIQ assessed control in relation to illness more generally. The PBIQ assessed consequences in relation to loss of autonomy, whereas the SRM based measures assessed consequences in relation to impact on life more generally. This variation in illness perception dimensions assessed makes it more difficult to compare and synthesis findings. Additionally, some studies carried out analyses using total scores, which are less informative as the total score does not enable the assessment of the relationships of separate illness perceptions dimensions with outcomes. Furthermore, the included studies demonstrated that there is variation in the relationships between dimensions of illness perceptions and therefore using the total score could lead to a dilution of these effects.

Outcomes of interest

The outcomes of interests included in the present review were broad, in line with NICE Guidelines (NICE, 2014a). As CBTp aims to reduce distress, rather than symptoms, it makes sense to include these outcomes when assessing the effectiveness of the intervention. However, there is no consensus over which outcomes may be the most meaningful. In severe mental illness there have been outcome measures developed in collaboration with service users, including the CHOICE questionnaire, which aims to reflect more strongly the priorities of service users and the aims of CBTp rather than symptom reduction (Greenwood et al., 2010); the 'Questionnaire about the Process of Recovery' which defines recovery from service users' perspective (Neil et al., 2009); and the QoL.BD which is quality of life measure that is designed to be more sensitive to day to day user-identified change in bipolar symptomatology. These user led outcomes move away from those traditionally imposed by clinicians and researchers and allow outcomes to be assessed in a way that is meaningful for service users. It is notable that no study in the current review considered these measures, and this highlights a key area for future research.

Strengths of the present review

This review included measures of illness perceptions that are based on a range of psychological models. This includes the namely the SRM, assessed by variations of the IPQ and social rank theory, assessed by the PBIQ. A previous review across conditions restricted the scope of included studies to those which had used measures based on the SRM (Baines & Wittkowski, 2013). Lobban et al. (2003) discussed the validity of the SRM in mental health and highlighted a limitation in that measures based on it do not ask about illness perceptions within a social context. Ten studies in the present review used the PBIQ to examine illness perceptions in the context of social rank theory. This theory proposes that an individual's perceptions of attractiveness and acceptability to others confirms their social rank within an interpersonal and social context (Gilbert, 2000). Perceptions of lower rank have been associated with increased risk of physical and psychological stress as a result of the differential position (Wilkinson, 1997). Included studies which utilised the PBIQ found that baseline perceptions of humiliation and self as illness predicted distress outcomes at three and 12 month follow up and that some of these dimensions of perceptions are able to change over time or during CBTp. This demonstrates the importance of considering the social context of illness perceptions.

Lobban et al. (2003) highlighted another limitation of the SRM in that it did not assess perceptions of specific treatments. This is not about whether illness would be amenable to treatment in general but rather about the perceived effectiveness of specific treatment e.g. talking therapy. Questions assessing perceptions of treatability in general do not differentiate between different types of treatment e.g. medication and talking therapy, which are likely to vary. One included study developed a modified version of the IPQ which added three items which assessed attitudes towards CBT principles e.g. "Changing the way I think or the way I do things can improve my problems" within a cure/control subscale which predicted symptoms severity in relation to paranoia (Marcus et al., 2014). This suggests that perceptions about specific treatments could be helpful to assess, beyond perceptions about the treatability of illness in general.

Areas for further research

This review highlighted the limited number of clinical trials investigating the relationship between illness perceptions and outcomes in psychosis and bipolar. It would be beneficial to use this methodology to examine these relationships further, especially in relation to recommended treatments such as psychological or psychosocial interventions (NICE, 2014a, 2014b). Findings to date suggests that some illness perceptions dimensions are amenable to change through CBT or psychoeducation. Change in overall illness perceptions was associated with change in social functioning (Etain et al., 2018), however further research is needed to understand causal mechanisms.

Other potential areas of further research include: examining whether patterns of illness perceptions across dimensions could increase predictive value; understanding the interactions between primary and secondary appraisals, especially in at risk groups or across the continuum of anomalous experiences with or without a 'need for care'; investigating the link between illness perceptions and compulsory treatment or hospital admissions which may increase feelings of hopelessness and defeat; exploring illness perceptions within cultural contexts; understanding the ambiguities with some dimensions of illness perceptions, including the conceptualisation of timeline; grandiosity and interactions with illness perceptions and outcomes, further understanding of causal attributions and links to outcomes; and the utilisation of user led measures in the context of illness perceptions to assess meaningful outcomes for service users.

Conclusion

This review explored the relationships between illness perceptions and outcomes in psychosis and bipolar. Thirty-three studies were included, which varied in design, measurement of both illness perceptions and outcomes of interest, methodological quality and inconsistency in findings which limits the conclusions that can be drawn. However, overall the studies demonstrated that more positive or adaptive illness perceptions were associated with better outcomes, including psychological distress, wellbeing, quality of life, functioning, positive symptoms, and engagement in CBTp or psychoeducation interventions. However, as these findings were largely from cross-sectional analyses, causal inferences are limited to findings from few studies. A limited number of longitudinal studies demonstrated variation in stability of illness perceptions over time without specific interventions and that perceptions of control and loss could improve during CBT and psychoeducation intervention. Further intervention studies are needed to provide more evidence on the potential for changeability of illness perceptions and importantly to understand whether change in illness perceptions is related to outcomes.

References

Acosta, F. J., Aguilar, E. J., Cejas, M. R., & Gracia, R. (2013). Beliefs about illness and their relationship with hopelessness, depression, insight and suicide attempts in schizophrenia. *Psychiatria Danubina, 25*(1), 0-54.

Amador, X. F., Strauss, D. H., Yale, S. A., Flaum, M. M., Endicott, J., & Gorman, J. M. (1993). Assessment of insight in psychosis. *American journal of Psychiatry, 150*, 873-873.

Awan, N. R., Jehangir, S. F., Irfan, M., Naeem, F., & Farooq, S. (2017). Explanatory model of illness of the patients with schizophrenia and the role of educational intervention. *Schizophrenia research, 190*, 68-73.

Baines, T., & Wittkowski, A. (2013). A systematic review of the literature exploring illness perceptions in mental health utilising the self-regulation model. *Journal of clinical psychology in medical settings, 20*(3), 263-274.

Berk, M., Berk, L., Dodd, S., Fitzgerald, P. B., de Castella, A. R., Filia, S., . . . Montgomery, W. (2013). The sick role, illness cognitions and outcomes in bipolar disorder. *Journal of affective disorders, 146*(1), 146-149.

Birchwood, M., Iqbal, Z., & Upthegrove, R. (2005). Psychological pathways to depression in schizophrenia. *European archives of psychiatry and clinical neuroscience, 255*(3), 202-212.

Birchwood, M., Mason, R., MacMillan, F., & Healy, J. (1993). Depression, demoralization and control over psychotic illness: a comparison of depressed and non-depressed patients with a chronic psychosis. *Psychological medicine, 23*(2), 387-395.

Broadbent, E., Kydd, R., Sanders, D., & Vanderpyl, J. (2008). Unmet needs and treatment seeking in high users of mental health services: role of illness perceptions. *Australian & New Zealand Journal of Psychiatry, 42*(2), 147-153.

Broadbent, E., Wilkes, C., Koschwanez, H., Weinman, J., Norton, S., & Petrie, K. J. (2015). A systematic review and meta-analysis of the Brief Illness Perception Questionnaire. *Psychol Health, 30*(11), 1361-1385. doi:10.1080/08870446.2015.1070851

Cavelti, M., Beck, E. M., Kvrgic, S., Kossowsky, J., & Vauth, R. (2012a). The role of subjective illness beliefs and attitude toward recovery within the relationship of insight and depressive symptoms among people with schizophrenia spectrum disorders. *Journal of clinical psychology, 68*(4), 462-476.

Cavelti, M., Contin, G., Beck, E.-M., Kvrgic, S., Kossowsky, J., Stieglitz, R.-D., & Vauth, R. (2012b). Validation of the Illness Perception Questionnaire for Schizophrenia in a German-speaking sample of outpatients with chronic schizophrenia. *Psychopathology, 45*(4), 259-269.

Chadwick, P., Williams, C., & Mackenzie, J. (2003). Impact of case formulation in cognitive behaviour therapy for psychosis. *Behaviour research and therapy, 41*(6), 671-680.

Chang, C.-K., Hayes, R. D., Perera, G., Broadbent, M. T. M., Fernandes, A. C., Lee, W. E., . . . Stewart, R. (2011). Life expectancy at birth for people with serious mental illness and other major disorders from a secondary mental health care case register in London. *PloS one, 6*(5).

Charles, C., Ninot, G., & Sultan, S. (2011). Patients' illness perceptions and adherence to treatment with inhaled corticosteroids in asthma. *Revue des maladies respiratoires, 28*(5), 626-635.

Clarke, A. L., Yates, T., Smith, A. C., & Chilcot, J. (2016). Patient's perceptions of chronic kidney disease and their association with psychosocial and clinical outcomes: a narrative review. *Clin Kidney J, 9*(3), 494-502. doi:10.1093/ckj/sfw014

Cosoff, S. J., & Hafner, R. J. (1998). The prevalence of comorbid anxiety in schizophrenia, schizoaffective disorder and bipolar disorder. *Australian and New Zealand Journal of Psychiatry, 32*(1), 67-72.

Drury, V., Birchwood, M., & Cochrane, R. (2000). Cognitive therapy and recovery from acute psychosis: A controlled trial: 3. Five-year follow-up. *The British Journal of Psychiatry, 177*(1), 8-14.

Dunn, G., Fowler, D., Rollinson, R., Freeman, D., Kuipers, E., Smith, B., . . . Garety, P. (2012). Effective elements of cognitive behaviour therapy for psychosis: results of a novel type of subgroup analysis based on principal stratification. *Psychological medicine, 42*(5), 1057-1068.

Dutta, R., Murray, R. M., Hotopf, M., Allardyce, J., Jones, P. B., & Boydell, J. (2010). Reassessing the long-term risk of suicide after a first episode of psychosis. *Archives of general psychiatry, 67*(12), 1230-1237.

Etain, B., Scott, J., Cochet, B., Bellivier, F., Boudebesse, C., Drancourt, N., . . . Fouques, D. (2018). A study of the real-world effectiveness of group psychoeducation for bipolar disorders: Is change in illness perception a key mediator of benefit? *Journal of affective disorders, 227*, 713-720.

Fialko, L., Freeman, D., Bebbington, P. E., Kuipers, E., Garety, P. A., Dunn, G., & Fowler, D. (2006). Understanding suicidal ideation in psychosis: findings from the Psychological Prevention of Relapse in Psychosis (PRP) trial. *Acta Psychiatrica Scandinavica, 114*(3), 177-186.

Freeman, D., Dunn, G., Garety, P., Weinman, J., Kuipers, E., Fowler, D., . . . Bebbington, P. (2013). Patients' beliefs about the causes, persistence and control of psychotic experiences predict take-up of effective cognitive behaviour therapy for psychosis. *Psychological medicine, 43*(2), 269-277.

Garety, P. A., Fowler, D. G., Freeman, D., Bebbington, P., Dunn, G., & Kuipers, E. (2008). Cognitive-behavioural therapy and family intervention for relapse prevention and symptom reduction in psychosis: randomised controlled trial. *The British Journal of Psychiatry, 192*(6), 412-423.

Garety, P. A., Kuipers, E., Fowler, D., Freeman, D., & Bebbington, P. (2001). A cognitive model of the positive symptoms of psychosis. *Psychological medicine, 31*(2), 189-195.

Gilbert, P. (2000). Varieties of submissive behavior as forms of social defense: Their evolution and role in depression.

Gómez-de-Regil, L. (2015). Insight and illness perception in Mexican patients with psychosis. *Schizophrenia Research: Cognition, 2*(1), 33-38.

Gómez-de-Regil, L., Kwapil, T. R., & Barrantes-Vidal, N. (2014). Illness perception mediates the effect of illness course on the quality of life of Mexican patients with psychosis. *Applied Research in Quality of Life, 9*(1), 99-112.

Greenwood, K. E., Sweeney, A., Williams, S., Garety, P., Kuipers, E., Scott, J., & Peters, E. (2010). CHoice of Outcome In Cbt for psychosEs (CHOICE): the development of a new service user–led outcome measure of CBT for psychosis. *Schizophrenia Bulletin, 36*(1), 126-135.

Gumley, A., Karatzias, A., Power, K., Reilly, J., McNay, L., & O'Grady, M. (2006). Early intervention for relapse in schizophrenia: Impact of cognitive behavioural therapy on negative beliefs about psychosis and self-esteem. *British Journal of Clinical Psychology, 45*(2), 247-260.

Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and health, 18*(2), 141-184.

Hartley, S., Barrowclough, C., & Haddock, G. (2013). Anxiety and depression in psychosis: a systematic review of associations with positive psychotic symptoms. *Acta Psychiatrica Scandinavica, 128*(5), 327-346.

Higgins, J. P. T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M. J., & Welch, V. A. (2019). *Cochrane handbook for systematic reviews of interventions*: John Wiley & Sons.

Iqbal, Z., Birchwood, M., Chadwick, P., & Trower, P. (2000). Cognitive approach to depression and suicidal thinking in psychosis: 2. Testing the validity of a social ranking model. *The British Journal of Psychiatry, 177*(6), 522-528.

Johns, L., Jolley, S., Garety, P., Khondoker, M., Fornells-Ambrojo, M., Onwumere, J., . . . Byrne, M. (2019). Improving Access to psychological therapies for people with severe mental illness (IAPT-SMI): Lessons from the South London and Maudsley psychosis demonstration site. *Behaviour research and therapy, 116*, 104-110.

Karatzias, T., Gumley, A., Power, K., & O'Grady, M. (2007). Illness appraisals and self-esteem as correlates of anxiety and affective comorbid disorders in schizophrenia. *Comprehensive Psychiatry, 48*(4), 371-375.

Leventhal, H., Meyer, D., & Nerez, D. (1980). The common sense model of illness danger In Rachman S., editor.(Ed.), Medical psychology volume 2 (pp. 7–30). In: New York, NY: Pergamon.

Leventhal, H., Nerenz, D., & Steele, D. (1984). Illness representations and coping with health threats. In A. B. J. Singer (Ed.), *A handbook of psychology and health* (pp. 219 – 252). Hillsdale, NJ: Erlbaum.

Lobban, F., Barrowclough, C., & Jones, S. (2003). A review of the role of illness models in severe mental illness. *Clinical psychology review, 23*(2), 171-196.

Lobban, F., Barrowclough, C., & Jones, S. (2004). The impact of beliefs about mental health problems and coping on outcome in schizophrenia. *Psychological medicine, 34*(7), 1165-1176.

Lobban, F., Barrowclough, C., & Jones, S. (2005). Assessing cognitive representations of mental health problems. I. The illness perception questionnaire for schizophrenia. *British Journal of Clinical Psychology, 44*(2), 147-162.

Lobban, F., Solis-Trapala, I., Tyler, E., Chandler, C., Morriss, R. K., & Group, E. R. P. (2013). The role of beliefs about mood swings in determining outcome in bipolar disorder. *Cognitive therapy and research, 37*(1), 51-60.

Maguire, P. A., Reay, R. E., & Raphael, B. (2016). Correlates of a single-item Self-Rated Mental Health Question in people with schizophrenia. *Australasian Psychiatry, 24*(5), 473-477.

Marcus, E., Garety, P., Weinman, J., Emsley, R., Dunn, G., Bebbington, P., . . . Hardy, A. (2014). A pilot validation of a modified Illness Perceptions Questionnaire designed to predict response to cognitive therapy for psychosis. *Journal of behavior therapy and experimental psychiatry, 45*(4), 459-466.

McCabe, R., & Priebe, S. (2004). Assessing the stability of schizophrenia patients' explanatory models of illness over time. *Journal of Mental Health, 13*(2), 163-169.

McGlashan, T. H., & Carpenter, W. T. (1981). Does attitude toward psychosis relate to outcome? *The American journal of psychiatry*.

Moriarty, A., Jolley, S., Callanan, M. M., & Garety, P. (2012). Understanding reduced activity in psychosis: the roles of stigma and illness appraisals. *Social Psychiatry and Psychiatric Epidemiology, 47*(10), 1685-1693.

Morrison, A. P. (2001). The interpretation of intrusions in psychosis: an integrative cognitive approach to hallucinations and delusions. *Behavioural and Cognitive Psychotherapy, 29*(3), 257-276.

Murphy, J., McSharry, J., Hynes, L., Matthews, S., Van Rhoon, L., & Molloy, G. J. (2020). Prevalence and predictors of adherence to inhaled corticosteroids in young adults (15-30 years) with asthma: a systematic review and meta-analysis. *J Asthma*, 1-23. doi:10.1080/02770903.2020.1711916

Neil, S. T., Kilbride, M., Pitt, L., Nothard, S., Welford, M., Sellwood, W., & Morrison, A. P. (2009). The questionnaire about the process of recovery (QPR): a measurement tool developed in collaboration with service users. *Psychosis, 1*(2), 145-155.

NICE. (2014a). *Psychosis and schizophrenia in adults: Prevention and management*. Retrieved from https://www.nice.org.uk/guidance/cg178

NICE. (2014b). *Bipolar disorder: assessment and management*. Retrieved from https://www.nice.org.uk/guidance/cg185

Proudfoot, J., Parker, G., Manicavasagar, V., Hadzi-Pavlovic, D., Whitton, A., Nicholas, J., . . . Burckhardt, R. (2012). Effects of adjunctive peer support on perceptions of illness control and understanding in an online psychoeducation program for bipolar disorder: a randomised controlled trial. *Journal of affective disorders, 142*(1-3), 98-105.

Prytys, M., Garety, P. A., Jolley, S., Onwumere, J., & Craig, T. (2011). Implementing the NICE guideline for schizophrenia recommendations for psychological therapies: a qualitative analysis of the attitudes of CMHT staff. *Clinical psychology & psychotherapy, 18*(1), 48-59.

Rooke, O., & Birchwood, M. (1998). Loss, humiliation and entrapment as appraisals of schizophrenic illness: A prospective study of depressed and non-depressed patients. *British Journal of Clinical Psychology, 37*(3), 259-268.

Rosen, C., Marvin, R., Reilly, J. L., DeLeon, O., Harris, M. S. H., Keedy, S. K., . . . Sweeney, J. A. (2012). Phenomenology of first-episode psychosis in schizophrenia, bipolar disorder, and unipolar depression: a comparative analysis. *Clinical schizophrenia & related psychoses, 6*(3), 145-151A.

Ross, S., Walker, A., & MacLeod, M. J. (2004). Patient compliance in hypertension: role of illness perceptions and treatment beliefs. *J Hum Hypertens, 18*(9), 607-613. doi:10.1038/sj.jhh.1001721

Rössler, W., Salize, H. J., van Os, J., & Riecher-Rössler, A. (2005). Size of burden of schizophrenia and psychotic disorders. *European Neuropsychopharmacology, 15*(4), 399-409.

Rothstein, H. R., Sutton, A. J., & Borenstein, M. (2005). Publication bias in meta-analysis. *Publication bias in meta-analysis: Prevention, assessment and adjustments*, 1-7.

Saunders, J. C. (2003). Families living with severe mental illness: A literature review. *Issues in mental health nursing, 24*(2), 175-198.

Shah, P., Hull, T., & Riley, G. A. (2009). Associations between the Illness Perception Questionnaire for Schizophrenia and engagement in treatment in a secure setting. *Clinical Psychologist, 13*(2), 69-74.

Stainsby, M., Sapochnik, M., Bledin, K., & Mason, O. J. (2010). Are attitudes and beliefs about symptoms more important than symptom severity in recovery from psychosis? *Psychosis, 2*(1), 41-49.

Theodore, K., Johnson, S., Chalmers-Brown, A., Doherty, R., Harrop, C., & Ellett, L. (2012). Quality of life and illness beliefs in individuals with early psychosis. *Social Psychiatry and Psychiatric Epidemiology, 47*(4), 545-551.

Thomas, B. H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. *Worldviews on Evidence-Based Nursing, 1*(3), 176-184.

Watson, P. W. B., Garety, P. A., Weinman, J., Dunn, G., Bebbington, P. E., Fowler, D., . . . Kuipers, E. (2006). Emotional dysfunction in schizophrenia spectrum psychosis: the role of illness perceptions. *Psychological medicine, 36*(6), 761-770.

Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: a new method for assessing the cognitive representation of illness. *Psychology and health, 11*(3), 431-445.

White, R. G., McCleery, M., Gumley, A. I., & Mulholland, C. (2007). Hopelessness in schizophrenia: the impact of symptoms and beliefs about illness. *The Journal of nervous and mental disease, 195*(12), 968-975.

Wilkinson, R. G. (1997). Socioeconomic determinants of health: Health inequalities: relative or absolute material standards? *Bmj, 314*(7080), 591.

Williams, K., & Steer, H. (2011). Illness perceptions: are beliefs about mental health problems associated with self-perceptions of engagement in people with psychosis? *Behavioural and Cognitive Psychotherapy, 39*(2), 151-163.

Appendix A: OVID exported search 2018

1	(psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking).ab,ti.	22981570	Advanced
2	(belief adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking)).ab,ti.	4214	Advanced
3	(appraisal adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking)).ab,ti.	2460	Advanced
4	(attitude adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking)).ab,ti.	6981	Advanced
5	(illness adj3 (perception* or identity* or representation* or self-perception* or attitude* or cogniti* or schema*)).ab,ti.	15036	Advanced
6	"common sense model*".ab,ti.	812	Advanced
7	"self-regulat* model".ab,ti.	961	Advanced
8	perceived control.ab,ti.	7199	Advanced
9	"personal model*".ab,ti.	238	Advanced
10	self-stigma.ab,ti.	1931	Advanced
11	"explanatory model*".ab,ti.	6482	Advanced
12	(caus* adj3 explanation*).ab,ti.	4406	Advanced
13	"internali*ed stigma".ab,ti.	1617	Advanced
14	self-label.ab,ti.	109	Advanced
15	self-concept.ab,ti.	28098	Advanced
16	"patient* perception*".ab,ti.	23488	Advanced
17	("common sense model*" or "self-regulat* model" or perceived control or "personal model*" or self-stigma or "explanatory model*" or (caus* adj3 explanation*) or "internali*ed stigma" or self-label or self-concept or "patient* perception*").ab,ti.	74415	Advanced
18	(IPQ or "illness perception* questionnaire" or BIPQ or brief-IPQ or IPQ-B or IPR-R or "revised illness perception questionnaire").ab,ti.	2679	Advanced
19	(psychosis or psychotic or schizophren* or bipolar or bi-polar or unusual experiences or mania or hallucinations or delusion* or paranoi* or ARMS or "at risk mental state" or "ultra high risk" or (voice* adj3 hearing)).ab,ti.	807091	Advanced
20	(CBT or "cognitive behavio* therapy").ab,ti.	58190	Advanced
21	(voices or delusions).ab,ti.	49814	Advanced
22	((CBT or "cognitive behavio* therapy") and (voices or delusions)).ab,ti.	720	Advanced
23	((belief adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking)) or (belief adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking)) or (attitude adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking)) or (illness adj3 (perception* or identity* or representation* or self-perception* or attitude* or cogniti* or schema*)) or "common sense model*" or "self-regulat* model" or perceived control or "personal model*" or self-stigma or "explanatory model*" or (caus* adj3 explanation*) or "internali*ed stigma" or self-label or self-concept or "patient* perception*" or ("common sense model*" or "self-regulat* model" or perceived control or "personal model*" or self-stigma or "explanatory model*" or (caus* adj3 explanation*) or "internali*ed stigma" or self-label or self-concept or "patient* perception*") or (IPQ or "illness perception* questionnaire" or BIPQ or brief-IPQ or IPQ-B or IPR-R or "revised illness perception questionnaire")).ab,ti.	97193	Advanced

24	(psychosis or psychotic or schizophren* or bipolar or bi-polar or unusual experiences or mania or hallucinations or delusion* or paranoi* or ARMS or "at risk mental state" or "ultra high risk" or (voice* adj3 hearing) or ((CBT or "cognitive behavio* therapy") and (voices or delusions))).ab,ti.	807118	Advanced
25	(((belief adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking)) or (belief adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking)) or (attitude adj3 (psychosis or diagnosis or symptoms or timeline or chronic* or control or cure or caus* or consequence* or illness or treatment or therapy or psychotherapy or CBT or CBTp or "mental health" or medication or help-seeking)) or (illness adj3 (perception* or identity* or representation* or self-perception* or attitude* or cogniti* or schema*)) or "common sense model*" or "self-regulat* model" or perceived control or "personal model*" or self-stigma or "explanatory model*" or (caus* adj3 explanation*) or "internali*ed stigma" or self-label or self-concept or "patient* perception*" or ("common sense model*" or "self-regulat* model" or perceived control or "personal model*" or self-stigma or "explanatory model*" or (caus* adj3 explanation*) or "internali*ed stigma" or self-label or self-concept or "patient* perception*") or (IPQ or "illness perception* questionnaire" or BIPQ or brief-IPQ or IPQ-B or IPR-R or "revised illness perception questionnaire")) and (psychosis or psychotic or schizophren* or bipolar or bi-polar or unusual experiences or mania or hallucinations or delusion* or paranoi* or ARMS or "at risk mental state" or "ultra high risk" or (voice* adj3 hearing) or ((CBT or "cognitive behavio* therapy") and (voices or delusions)))).ab,ti.	5527	Advanced
26	limit 25 to english language	4936	Advanced
27	limit 26 to yr="1980 -Current"	4743	Advanced
28	remove duplicates from 27	2634	

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

1 Very likely
2 Somewhat likely
3 Not likely
4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

1 80 - 100% agreement
2 60 – 79% agreement
3 less than 60% agreement
4 Not applicable
5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

1 Randomized controlled trial
2 Controlled clinical trial
3 Cohort analytic (two group pre + post)
4 Case-control
5 Cohort (one group pre + post (before and after))
6 Interrupted time series
7 Other specify _____
8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1 Yes
2 No
3 Can't tell

The following are examples of confounders:

1 Race
2 Sex
3 Marital status/family
4 Age
5 SES (income or class)
6 Education
7 Health status
8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1 80 – 100% (most)
2 60 – 79% (some)
3 Less than 60% (few or none)
4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1 Yes
2 No
3 Can't tell

(Q2) Were the study participants aware of the research question?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1 Yes
2 No
3 Can't tell

(Q2) Were data collection tools shown to be reliable?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1 Yes
2 No
3 Can't tell
4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell
5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell

(Q2) Was the consistency of the intervention measured?

1 Yes
2 No
3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

4 Yes
5 No
6 Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

1 Yes
2 No
3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1 Yes
2 No
3 Can't tell

GLOBAL RATING

COMPONENT RATINGS
Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	**SELECTION BIAS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
B	**STUDY DESIGN**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
C	**CONFOUNDERS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
D	**BLINDING**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
E	**DATA COLLECTION METHOD**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
F	**WITHDRAWALS AND DROPOUTS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1	STRONG	(no WEAK ratings)
2	MODERATE	(one WEAK rating)
3	WEAK	(two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

1	Oversight
2	Differences in interpretation of criteria
3	Differences in interpretation of study

Final decision of both reviewers (circle one):

1	**STRONG**
2	**MODERATE**
3	**WEAK**

Component Ratings of Study:

For each of the six components A – F, use the following descriptions as a roadmap.

A) SELECTION BIAS

Good: The selected individuals are very likely to be representative of the target population (Q1 is 1) **and** there is greater than 80% participation (Q2 is 1).

Fair: The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); **and** there is 60 - 79% participation (Q2 is 2). 'Moderate' may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can't tell).

Poor: The selected individuals are not likely to be representative of the target population (Q1 is 3); **or** there is less than 60% participation (Q2 is 3) **or** selection is not described (Q1 is 4); and the level of participation is not described (Q2 is 5).

B) DESIGN

Good: will be assigned to those articles that described RCTs and CCTs.

Fair: will be assigned to those that described a cohort analytic study, a case control study, a cohort design, or an interrupted time series.

Weak: will be assigned to those that used any other method or did not state the method used.

C) CONFOUNDERS

Good: will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); **or** (Q2 is 1).

Fair: will be given to those studies that controlled for 60 – 79% of relevant confounders (Q1 is 1) **and** (Q2 is 2).

Poor: will be assigned when less than 60% of relevant confounders were controlled (Q1 is 1) **and** (Q2 is 3) **or** control of confounders was not described (Q1 is 3) **and** (Q2 is 4).

D) BLINDING

Good: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **and** the study participants are not aware of the research question (Q2 is 2).

Fair: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **or** the study participants are not aware of the research question (Q2 is 2).

Poor: The outcome assessor is aware of the intervention status of participants (Q1 is 1); **and** the study participants are aware of the research question (Q2 is 1); **or** blinding is not described (Q1 is 3 and Q2 is 3).

E) DATA COLLECTION METHODS

Good: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have been shown to be reliable (Q2 is 1).

Fair: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have not been shown to be reliable (Q2 is 2) **or** reliability is not described (Q2 is 3).

Poor: The data collection tools have not been shown to be valid (Q1 is 2) **or** both reliability and validity are not described (Q1 is 3 and Q2 is 3).

F) WITHDRAWALS AND DROP-OUTS - a rating of:

Good: will be assigned when the follow-up rate is 80% or greater (Q1 is 1 and Q2 is 1).

Fair: will be assigned when the follow-up rate is 60 – 79% (Q2 is 2) **OR** Q1 is 4 or Q2 is 5.

Poor: will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q1 is No or Q2 is 4).

Not Applicable: if Q1 is 4 or Q2 is 5.

Appendix C: Quality Assessment Tool for Quantitative Studies (QATQ) Dictionary

Quality Assessment Tool for Quantitative Studies Dictionary

The purpose of this dictionary is to describe items in the tool thereby assisting raters to score study quality. Due to under-reporting or lack of clarity in the primary study, raters will need to make judgements about the extent that bias may be present. When making judgements about each component, raters should form their opinion based upon information contained in the study rather than making inferences about what the authors intended. Mixed methods studies can be quality assessed using this tool with the quantitative component of the study.

A) SELECTION BIAS

(Q1) Participants are more likely to be representative of the target population if they are randomly selected from a comprehensive list of individuals in the target population (score very likely). They may not be representative if they are referred from a source (e.g. clinic) in a systematic manner (score somewhat likely) or self-referred (score not likely).

(Q2) Refers to the % of subjects in the control and intervention groups that agreed to participate in the study before they were assigned to intervention or control groups.

B) STUDY DESIGN

In this section, raters assess the likelihood of bias due to the allocation process in an experimental study. For observational studies, raters assess the extent that assessments of exposure and outcome are likely to be independent. Generally, the type of design is a good indicator of the extent of bias. In stronger designs, an equivalent control group is present and the allocation process is such that the investigators are unable to predict the sequence.

Randomized Controlled Trial (RCT)

An experimental design where investigators randomly allocate eligible people to an intervention or control group. A rater should describe a study as an RCT if the randomization sequence allows each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. If the investigators do not describe the allocation process and only use the words 'random' or 'randomly', the study is described as a controlled clinical trial.

See below for more details.

Was the study described as randomized?

Score YES, if the authors used words such as random allocation, randomly assigned, and random assignment.

Score NO, if no mention of randomization is made.

Was the method of randomization described?

Score YES, if the authors describe any method used to generate a random allocation sequence.

Score NO, if the authors do not describe the allocation method or describe methods of allocation such as alternation, case record numbers, dates of birth, day of the week, and any allocation procedure that is entirely transparent before assignment, such as an open list of random numbers of assignments.
If NO is scored, then the study is a controlled clinical trial.

Was the method appropriate?

Score YES, if the randomization sequence allowed each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. Examples of appropriate approaches include assignment of subjects by a central office unaware of subject characteristics, or sequentially numbered, sealed, opaque envelopes.

Score NO, if the randomization sequence is open to the individuals responsible for recruiting and allocating participants or providing the intervention, since those individuals can influence the allocation process, either knowingly or unknowingly.

If NO is scored, then the study is a controlled clinical trial.

Controlled Clinical Trial (CCT)
An experimental study design where the method of allocating study subjects to intervention or control groups is open to individuals responsible for recruiting subjects or providing the intervention. The method of allocation is transparent before assignment, e.g. an open list of random numbers or allocation by date of birth, etc.

Cohort analytic (two group pre and post)
An observational study design where groups are assembled according to whether or not exposure to the intervention has occurred. Exposure to the intervention is not under the control of the investigators. Study groups might be non-equivalent or not comparable on some feature that affects outcome.

Case control study
A retrospective study design where the investigators gather 'cases' of people who already have the outcome of interest and 'controls' who do not. Both groups are then questioned or their records examined about whether they received the intervention exposure of interest.

Cohort (one group pre + post (before and after)
The same group is pretested, given an intervention, and tested immediately after the intervention. The intervention group, by means of the pretest, act as their own control group.

Interrupted time series
A study that uses observations at multiple time points before and after an intervention (the 'interruption'). The design attempts to detect whether the intervention has had an effect significantly greater than any underlying trend over time. Exclusion: Studies that do not have a clearly defined point in time when the intervention occurred and at least three data points before and three after the intervention

Other:
One time surveys or interviews

C) CONFOUNDERS

By definition, a confounder is a variable that is associated with the intervention or exposure and causally related to the outcome of interest. Even in a robust study design, groups may not be balanced with respect to important variables prior to the intervention. The authors should indicate if confounders were controlled in the design (by stratification or matching) or in the analysis. If the allocation to intervention and control groups is randomized, the authors must report that the groups were balanced at baseline with respect to confounders (either in the text or a table).

D) BLINDING

(Q1) Assessors should be described as blinded to which participants were in the control and intervention groups. The purpose of blinding the outcome assessors (who might also be the care providers) is to protect against detection bias.

(Q2) Study participants should not be aware of (i.e. blinded to) the research question. The purpose of blinding the participants is to protect against reporting bias.

E) DATA COLLECTION METHODS

Tools for primary outcome measures must be described as reliable and valid. If 'face' validity or 'content' validity has been demonstrated, this is acceptable. Some sources from which data may be collected are described below:

Self reported data includes data that is collected from participants in the study (e.g. completing a questionnaire, survey, answering questions during an interview, etc.).

Assessment/Screening includes objective data that is retrieved by the researchers. (e.g. observations by investigators).

Medical Records/Vital Statistics refers to the types of formal records used for the extraction of the data.

Reliability and validity can be reported in the study or in a separate study. For example, some standard assessment tools have known reliability and validity.

F) WITHDRAWALS AND DROP-OUTS

Score **YES** if the authors describe BOTH the numbers and reasons for withdrawals and drop-outs.

Score **NO** if either the numbers or reasons for withdrawals and drop-outs are not reported.

Score **NOT APPLICABLE** if the study was a one-time interview or survey where there was not follow-up data reported.

The percentage of participants completing the study refers to the % of subjects remaining in the study at the final data collection period in all groups (i.e. control and intervention groups).

G) INTERVENTION INTEGRITY

The number of participants receiving the intended intervention should be noted (consider both frequency and intensity). For example, the authors may have reported that at least 80 percent of the participants received the complete intervention. The authors should describe a method of measuring if the intervention was provided to all participants the same way. As well, the authors should indicate if subjects received an unintended intervention that may have influenced the outcomes. For example, co-intervention occurs when the study group receives an additional intervention (other than that intended). In this case, it is possible that the effect of the intervention may be over-estimated. Contamination refers to situations where the control group accidentally receives the study intervention. This could result in an under-estimation of the impact of the intervention.

H) ANALYSIS APPROPRIATE TO QUESTION

Was the quantitative analysis appropriate to the research question being asked?

An intention-to-treat analysis is one in which all the participants in a trial are analyzed according to the intervention to which they were allocated, whether they received it or not. Intention-to-treat analyses are favoured in assessments of effectiveness as they mirror the noncompliance and treatment changes that are likely to occur when the intervention is used in practice, and because of the risk of attrition bias when participants are excluded from the analysis.

Appendix D: Full details of quality ratings by Quality Assessment Tool for Quantitative Studies (QATQ)

Study ID	Overall rating	A			B			C			E			F		
		Selection bias			Study Design			Confounders			Data collection methods			Withdrawals and drop-outs		
		Q1	Q2	Score			Score	Q1	Q2	Score	Q1	Q2	Score	Q1	Q2	Score
Acosta 2013	Weak	2	5	Moderate	4	Case-control	Moderate	2	4	Weak	1	1	Strong	3	4	Weak
Awan 2017	Strong	2	1	Moderate	1	RCT	Strong	1	n/a	Strong	1	1	Strong	1	2	Moderate
Berk 2013	Weak	2	5	Moderate	7	CS	Weak	3	4	Weak	1	1	Strong	4	5	Moderate
Birchwood 1993	Moderate	1	5	Moderate	7	CS	Weak	2	n/a	Strong	1	1	Strong	4	5	Moderate
Birchwood 2005 Study 1	Weak	2	5	Moderate	3	Cohort	Moderate	3	4	Weak	1	1	Strong	2	4	Weak
Birchwood 2005 Study 3	Weak	3	2	Moderate	7	CS	Weak	3	4	Weak	1	1	Strong	3	4	Weak
Broadbent 2008	Weak	1	3	Weak	7	CS	Weak	3	4	Weak	1	1	Strong	4	5	Moderate
Cavelti 2012a	Weak	2	5	Moderate	7	CS	Weak	3	4	Weak	1	1	Strong	4	5	Moderate
Cavelti 2012b	Weak	2	2	Moderate	7	CS	Weak	3	4	Weak	1	1	Strong	4	5	Moderate
Drury 2008	Moderate	2	5	Moderate	2	Controlled trial	Strong	2	1	Strong	2	2	Weak	1	2	Moderate
Etain 2018	Weak	3	3	Weak	5	Cohort	Moderate	2	1	Strong	2	2	Weak	1	3	Weak
Fialko 2006	Moderate	2	5	Moderate	7	CS	Weak	2	n/a	Strong	1	1	Strong	4	5	Moderate
Freeman 2013	Strong	2	5	Moderate	5	Cohort	Moderate	2	n/a	Strong	1	1	Strong	1	5	Moderate
Gomez-de-Regil 2014	Moderate	2	2	Moderate	7	CS	Weak	2	n/a	Strong	1	1	Strong	4	5	Moderate
Gomez-de-Regil 2015	Moderate	2	2	Moderate	7	CS	Weak	2	n/a	Strong	1	1	Strong	4	5	Moderate
Gumley 2006	Strong	2	5	Moderate	1	RCT	Strong	2	1	Strong	1	1	Strong	1	1	Strong
Iqbal 2000	Moderate	2	5	Moderate	5	Cohort	Moderate	3	4	Weak	1	1	Strong	1	2	Moderate
Karatzias 2007	Moderate	2	5	Moderate	7	CS	Weak	2	1	Strong	1	1	Strong	4	5	Moderate
Lobban 2004	Strong	2	2	Moderate	5	Cohort	Moderate	1	1	Strong	1	1	Strong	1	1	Strong
Lobban 2005	Weak	2	2	Moderate	7	CS	Weak	3	4	Weak	1	1	Strong	1	1	Strong
Lobban 2013	Strong	2	5	Moderate	3	Cohort	Moderate	2	1	Strong	1	1	Strong	1	1	Strong
Maguire 2016	Weak	2	5	Moderate	7	CS	Weak	1	1	Strong	2	2	Weak	4	5	Moderate
Marcus 2014	Moderate	2	5	Moderate	5	Cohort	Moderate	2	n/a	Strong	1	1	Strong	3	4	Weak
McCabe 2004	Weak	2	5	Moderate	5	Cohort	Moderate	3	4	Weak	1	1	Strong	3	4	Weak

Study ID	Overall rating	A			B			C			E			F		
		Selection bias			Study Design			Confounders			Data collection methods			Withdrawals and drop-outs		
		Q1	Q2	Score			Score	Q1	Q2	Score	Q1	Q2	Score	Q1	Q2	Score
McGlashan 1981	Weak	2	5	Moderate	7	CS	Weak	3	4	Weak	1	1	Strong	4	5	Moderate
Moriarty 2012	Moderate	2	5	Moderate	7	CS	Weak	2	n/a	Strong	1	1	Strong	4	5	Moderate
Proudfoot 2012	Moderate	3	5	Weak	1	RCT	Strong	2	n/a	Strong	1	1	Strong	1	2	Moderate
Rooke 1998	Moderate	2	1	Moderate	5	Cohort	Moderate	3	4	Weak	1	1	Strong	1	1	Strong
Shah 2009	Weak	2	3	Weak	7	CS	Weak	3	4	Weak	1	1	Strong	4	5	Moderate
Stainsby 2010	Moderate	2	3	Weak	5	Cohort	Moderate	2	n/a	Strong	1	1	Strong	1	2	Moderate
Theodore 2012	Weak	2	3	Weak	7	CS	Weak	2	n/a	Strong	1	1	Strong	4	5	Moderate
Watson 2006	Weak	2	5	Moderate	7	CS	Weak	3	4	Weak	1	1	Strong	1	2	Moderate
White 2007	Weak	2	1	Moderate	7	CS	Weak	3	4	Weak	1	1	Strong	4	5	Moderate

CS = cross-sectional, RCT = randomised controlled trial

Empirical Research Project

The role of illness perceptions on engagement and psychological outcomes in Cognitive Behavioural Therapy for Psychosis (CBTp)

Supervised by

Dr Suzanne Jolley

Dr John Hodsoll

Dr Rebecca Kelly

The role of illness perceptions on engagement and psychological outcomes in Cognitive Behavioural Therapy for Psychosis (CBTp)

Abstract

Introduction

Illness perceptions are important mechanisms of engagement and change in physical health interventions and emerging evidence suggests they may play a similar role in psychological therapies, including the cognitive behavioural interventions recommended for psychosis and bipolar (CBTp). The limited number of CBTp studies to date that have investigated the role of illness perceptions have demonstrated that CBTp can improve illness perceptions and that this may relate to some outcomes. This relationship needs to be further understood to ascertain the potential to improve outcomes and effectiveness of treatment by specifically targeting illness perceptions in therapy.

Aim

The present studied aimed to further understand the relationships between change in dimensions of illness perceptions and outcomes in CBTp, including the direction of these relationships.

Method

A prospective cohort design was utilised with data collected as part of routine care across three time points: pre-therapy, mid-therapy and post-therapy. A modified version of the Brief Illness Perceptions Questionnaire (BIPQ) assessed ten dimensions of illness perceptions and the CORE-10 assessed levels of distress. Engagement was dichotomised as attending five or more therapy sessions (engaged) or ≤ 4 sessions (did not engage). Cross Lagged Panel Models (CLPM) were used to assess causal relationships between separate dimensions of illness perceptions and levels of distress during therapy.

Results

Two dimensions of illness perceptions predicted engagement in therapy. Those who in engaged in therapy (n = 305) had perceptions of less personal control over their mental health problems but higher perceptions that talking therapy would be helpful than those who did not engage (n = 305). The subsample (n = 248) of participants with sufficient data to be included in CLPM analyses showed that, during therapy, illness perceptions predicted change in levels of distress, for perceptions of symptom identity and that changing the way you think or do things can improve mental health. Levels of distress predicted change in illness perceptions across six dimensions including: consequences, personal control, identity, concern, coherence, emotional response, changing the way you think or do things can improve mental health, and looking at things differently as helpful. No causal effects were found for either perceptions of timeline or treatment control with levels of distress in either direction.

Conclusion

These findings suggest a strong causal role for distress on illness perceptions which has been neglected in previous research. Findings are potentially supportive of the possibility of incorporating explicit illness perception interventions into CBTp, but highlight the need for further controlled, longitudinal studies.

The role of illness perceptions on engagement and psychological outcomes in Cognitive Behavioural Therapy for Psychosis (CBTp)

INTRODUCTION

Psychological and psychosocial interventions are recommended treatments for psychosis and bipolar (NICE, 2014a, 2014b). Cognitive Behavioural Therapy for anxiety and affective conditions has been adapted for psychosis (CBTp). It draws upon cognitive models of psychotic symptoms and aims to help through making sense of experiences, normalising, reducing distress, and improving functioning while working towards personalised goals (Johns et al., 2019). CBT techniques and principles involve establishing links between thoughts, feelings and behaviours, building on coping skills, re-evaluating appraisals of symptoms, and relapse prevention. Evidence from service data and clinical trials has demonstrated beneficial effects of CBTp on positive symptoms, distress and functioning compared to routine care (NICE, 2014a).

Predictors of outcomes in CBTp

A limited number of studies have investigated potential change processes and drivers of outcomes in CBTp. Findings from the Psychological Prevention of Relapse in Psychosis (PRP) trial showed engagement moderated the effectiveness of CBTp for improving psychotic symptoms and levels of distress (Dunn et al., 2012). Findings indicated that engagement in full therapy, which included actively engaging in specific cognitive and behavioural strategies and interventions moderated these improvements, compared to partial therapy, categorised as including assessment and active attempts to engage in therapeutic techniques, which did not lead to improvements in symptoms and distress. This is in line with findings from single case studies, which suggested that the earlier stages of CBTp, which involve assessment and individual formulation and building a therapeutic relationship, do not lead to improvements in delusions and associated distress (Chadwick, Williams, & Mackenzie, 2003). Engagement in CBTp is mixed. When offered it is often only partially taken up (Garety et al., 2008) or refused (Prytys, Garety, Jolley, Onwumere, & Craig, 2011). A cohort CBT study found that take up of therapy was not predicted by severity of symptoms (Freeman et al., 2013). It is important to understand further what factors predict engagement in therapy, how they interact with outcomes, and whether they can be targeted and modified through intervention.

The role of illness perceptions in outcomes for psychosis and bipolar

Illness perceptions are beliefs about a specific illness in relation to key dimensions: its identity (what symptoms are attributed to it); cause (what is likely to have caused it); timeline (how long it is expected to last); consequences (impact on physical, social and psychological functioning); and cure and controllability (whether anything can be done to improve the condition and whether treatment could be effective). The self-regulation model (SRM) proposes that these individual perceptions of illness determine individual coping responses and health related behaviours (Leventhal, Nerenz, & Steele, 1984; Weinman, Petrie, Moss-Morris, & Horne, 1996). Illness perceptions have been extensively investigated in a physical health context. They have been found to impact on a variety of outcomes including psychological wellbeing and distress, social functioning and physical health (Hagger & Orbell, 2003). More positive or adaptive illness perceptions have also been associated with higher adherence to treatment, better self-management and physical health outcomes (Broadbent et al., 2015; Charles, Ninot, & Sultan, 2011; Clarke, Yates, Smith, & Chilcot, 2016; Murphy et al., 2020; Ross, Walker, & MacLeod, 2004). Illness perceptions have also been investigated somewhat in psychosis and bipolar.

Assessing illness perceptions in psychosis and bipolar poses a challenge due to the varying levels of insight in these conditions. In physical health, individuals would be required to recognise having a specific illness so that their beliefs about it could be assessed. However, illness perceptions measures have been adapted for use in psychosis by referring to "problems" or "difficulties" rather than a specific "illness" (Marcus et al., 2014). This increases flexibility as it does not rely on recognition of illness or attribution to internal or medical causes and therefore enables illness beliefs to be assessed in psychosis and bipolar, regardless of level of insight. Previous research has investigated the relationship between illness perceptions and insight. One study found correlations between insight, assessed by the Scale for the Unawareness of Mental Disorder (SUMD; Amador et al., 1993), and only the cure-control subscale of a modified version of the Illness Perception Questionnaire (Watson et al., 2006). A second study found that illness perceptions, assessed by the Personal Beliefs about Illness Questionnaire (Broadbent et al., 2006) correlated with levels of depression and hopelessness but not with insight, also assessed by the SUMD (Acosta, Aguilar, Cejas, & Gracia, 2013). The authors suggested that illness perceptions could change independent of level of awareness and that the role of insight may depend on psychological mediators (Acosta et al., 2013). Therefore, indicating that illness perceptions and insight are related but distinct concepts, whereby illness perceptions relate to aspects of personal meaning which are associated with affect and distinct from insight. This indicates the validity and importance of assessing illness perceptions when investigating outcomes in psychosis and bipolar.

Illness perceptions and engagement

The relationships between illness perceptions and a range of outcomes in psychosis and bipolar have predominantly been investigated using cross-sectional studies, with a limited number of studies utilising longitudinal and intervention designs. A cross-sectional study assessed illness perceptions of psychosis in relation to self-reported engagement. This was assessed using the "Action" score on the URICA readiness to change questionnaire (Hasler, Klaghofer, & Buddeberg, 2003) modified to suit a mental health context, based on the assumption it would be sensitive to engagement in therapy (Shah, Hull, & Riley, 2009). Findings indicated that better self-reported engagement (i.e. actively working on mental health problems) was associated with perceptions of a chronic and cyclical timeline and higher treatability. A cohort CBTp study found that those who took up full therapy had perceptions of a longer timeline compared to those who took up partial or no therapy (Freeman et al., 2013). Additionally, there were non-linear relationships with engagement, whereby perceptions of less cure/control were associated with partial take up of therapy, compared to none or full therapy. Etain et al. (2018) found that those who completed a three month psychoeducation intervention for bipolar had more adaptive/positive overall illness perceptions (total score) at baseline compared to those who dropped out.

Evidence from longitudinal studies

Longitudinal studies have found that baseline perceptions of less control over illness predicted higher levels of depression at follow up after 3 months (Birchwood, Iqbal, & Upthegrove, 2005), 12 months (Iqbal, Birchwood, Chadwick, & Trower, 2000) and 30 months (Rooke & Birchwood, 1998). Additionally, change in perceptions of control predicted depression at follow up (Rooke & Birchwood, 1998). Perceptions of worse consequences predicted poorer quality of life and less satisfaction with mental health after six months (Lobban, Barrowclough, & Jones, 2004), poorer quality of life after two years (Stainsby, Sapochnik, Bledin, & Mason, 2010), higher levels of depression after 6 months (Lobban et al., 2004), lower social and occupational functioning over after 24 weeks (Lobban et al., 2013), and increased the likelihood of greater fluctuations in depressed mood in bipolar over 24 weeks (Lobban et al., 2013). Perceptions of less personal effort to get well, also predicted increased likelihood of greater fluctuations in depressed mood (Lobban et al., 2013). Perceptions of a less coherent understanding, more emotional response and higher identity with symptoms predicted poorer quality of life at follow-up after two years (Stainsby et al., 2010). Longitudinal studies have also found that perceptions of more severe consequences, higher identification with symptoms and concern at baseline were associated with shorter time to relapse of psychosis symptoms during the following 24 weeks (Lobban et al., 2013).

There are very limited studies which have examined the relationship in the other direction. One study investigated the relationship with illness perceptions as the dependent variable and found that worse depression symptoms predicted more negative overall illness perceptions at 24 month follow up (Berk et

al., 2013). Additionally, compulsory admission to hospital and baseline perceptions of control predicted a decrease in perception of control over illness (Rooke & Birchwood, 1998). Not all studies have found effects: one study found no significant relationship between baseline illness perceptions between those who later relapsed over the following 12 months and those who did not (Iqbal et al., 2000) and another study did not find any significant association between illness perceptions at baseline and life skills at two year follow-up (Stainsby et al., 2010). Furthermore, within studies not all illness perception dimensions have been associated with outcomes. There has been variation in longitudinal studies to date in relation to design, measures of illness perceptions and outcomes, findings across dimensions, and the majority has assessed the relationship in one direction, with illness perceptions as the independent variable. Longitudinal studies are limited in terms of what can be inferred about causation.

Evidence from CBTp studies

A narrative review on illness perceptions in mental health, highlighted the potential for CBT trials to modify beliefs and demonstrate causal relationships (Lobban, Barrowclough, & Jones, 2003). However, only two CBTp studies have examined the potential for illness perceptions to change, but neither assessed whether this change was related to outcomes. Both studies assessed illness perceptions using the Personal Beliefs about Illness questionnaire (Birchwood, Mason, MacMillan, & Healy, 1993), which is based on social rank theory rather than the SRM. One study utilised a RCT design and specifically targeted two dimensions of illness perceptions: control over illness and humiliation (Drury, Birchwood, & Cochrane, 2000). Findings showed that overall the CBTp group reported significantly increased control over illness but no difference in humiliation at 5-year follow up compared to the control group who received recreational activities and support. No significant changes in illness perceptions were found for those not targeted by CBTp i.e. loss, shame or self as illness subscales.

Another study also utilised a RCT design for CBTp versus treatment as usual in an early intervention service and did not specifically target illness perceptions (Gumley et al., 2006). Findings showed that those who received CBTp showed reduced perceptions of loss, adjusted for baseline covariates. However, CBTp was not associated with improvements in perceived control, shame, humiliation and self as illness 12 month follow up. Additionally, change in illness perceptions were investigated as the dependent variable. After 12 months, those who had relapsed in psychosis symptoms showed greater decrease in control over illness and increase in self as illness compared to those who did not relapse, controlling for baseline covariates. This relationship was not assessed in relation to other outcomes, for example, distress, quality of life, functioning or engagement. However, a psychoeducation intervention for bipolar did find that change in overall illness perceptions (total score) was associated with change in social functioning (Etain et al., 2018). The role of engagement in these relationships was not assessed.

Aims and hypotheses

As in physical and other mental health conditions, there appears to be a relationship between illness perceptions and outcomes in psychosis and bipolar. However, this relationship needs to be further understood to ascertain the potential to improve outcomes and effectiveness of treatment by specifically targeting illness perceptions in therapy. Limited evidence from longitudinal studies has predominantly investigated the relationship with illness perceptions as the independent variable and found that they can predict some outcomes at follow up. Evidence from very limited CBTp studies suggest that some dimensions of illness perceptions are amenable to change, and that this change could be associated with some outcomes. However, the direction of these relationships is not clear and no studies to the author's knowledge have examined this relationship with distress outcomes. Additionally, the role of engagement has not been assessed in relation to change of illness perceptions and outcomes.

The present study aimed to further understand the relationships between change in dimensions of illness perceptions and outcomes in psychosis and bipolar, including the direction of these relationships. These relationships were studied within the context of CBTp as some dimensions of illness perceptions have previously shown they were changeable during this. Based on limited previous literature, the following hypotheses were proposed:

Hypotheses

1. More positive or adaptive illness perceptions prior to starting therapy will predict better engagement
2. Change to more positive or adaptive illness perceptions during CBTp will be associated with a reduction in psychological distress during therapy

An additional hypothesis was initially proposed to assess a potential mediating relationship: Better engagement in CBTp would predict a greater reduction in distress. However, there was not sufficient data at mid- and post-therapy time points from individuals with poorer engagement to test this hypothesis. As data for the present study came from a clinical service rather than a clinical trial, those who dropped out were not followed up to collect further data. This hypothesis could not therefore be tested.

Service user involvement

Service users were consulted in this project in two ways. The proposal was assessed by The NIHR Maudsley Biomedical Research Centre (BRC) service to researchers called FAST-R (Feasibility and Acceptability Support Team for Researchers). The feedback from reviewers included that they "felt this was an interesting study and that it is very important that barriers to therapeutic engagement are addressed and overcome." They also "felt the plan for service user and carer involvement was good, particularly involvement at multiple stages of the study."

The Peer Recovery Lead at the Psychological Interventions Clinic for outpatients with Psychosis (PICuP), the clinical service where data was collected from, was also consulted on the project proposal. Their perspectives were sought on the design of the study and on the measurement of illness perceptions and "engagement" in CBTp. Their perspective was based on their own experience of CBTp at PICuP and also the perspectives of other service users they had supported and had conversations with as part of their role. Feedback on the aims of the study were positive and illness perceptions were recognised as changing during therapy. In particular, an increase in perceptions of control was identified as an important component of therapy for its effectiveness i.e. "taking back control" and how it is down to the individual to make changes. Feelings of being "taken over" and "losing control over me" before starting therapy were reported to be more distressing compared to the content of anomalous experiences. Another key change in perception that occurred during therapy for this service user was a shift from viewing their anomalous experiences as terrifying to viewing them with curiosity and owning the lived experience. This resulted in a shift of feeling terrified by them, to fascinated. It was estimated that changes in illness perceptions occur around the middle of therapy or just after.

The challenges of capturing and measuring engagement within the scope of this project were discussed. The proxy measurement of engagement using number of therapy sessions attended has limitations as service users could attend therapy sessions but not engage in the content of the session. Lower attendance may instead reflect broader issues, for example, memory difficulties or if service users are not able to travel on their own, cancellations may occur for reasons related those accompanying them. Additionally, a culture of secrecy around accessing help around mental health may impact on service users' attendance for sessions. These issues were important to consider when interpreting findings recognising limitations of this study. Further details of discussions are included in appendix A.

METHOD

Participants

The population was working age adults receiving CBTp. Participants were selected using consecutive sampling of service users referred to PICuP, a specialist CBT service in South London which provides psychological interventions to distressed, help-seeking individuals with psychosis or with a history of psychosis and secondary emotional difficulties. Data was included from service users who had consented for their information to be used for service evaluation and research purposes. Their data was collected as part of routine clinical care from April 2013 to September 2019. Some service users received family intervention at the service and so were not included in the sample.

Design

This study utilised a prospective cohort design with data collected across three time points: pre-therapy, mid-therapy and post-therapy.

Procedure

In the first instance, service users were offered approximately 6 months of therapy sessions of CBTp. This is in line with the National Institute for Health and Care Excellence recommended guideline to offer at least 16 sessions (NICE, 2014a). The duration of therapy and number of sessions attended by each participant varied depending on patients' needs and engagement. The upper limit of sessions depended on the local funding agreements where services users were resident.

As part of routine clinical care service users were invited to attend a series of face to face assessments with an Assistant Psychologist to complete a pack of questionnaire measures. These assessments take place at the following time points:

1. Initial assessment: when referred and accepted into the service.
2. Pre-therapy assessment: prior to beginning therapy after being on the waiting list for approximately between four months but can vary between individuals based on locality funding circumstances.
3. Mid-therapy assessment: completed approximately halfway through therapy, typically after 3 months but would take place later if few therapy sessions have been attended.
4. Post-therapy assessment: typically within one week of completing therapy.

This study used data from pre-, mid- and post-therapy time points. Measures collected at initial assessment were used as baseline pre-therapy scores where appropriate. For instance, occasionally second assessments were not carried out due to therapy starting soon after the initial assessment. This occurred if, for example, service users were identified as being suitable to work with therapists training on the Doctorate in Clinical Psychology or CBTp diploma.

Measures

The primary variables of interest were illness perceptions, psychological distress and engagement in CBTp. Psychological distress was selected as the primary outcome because CBTp aims to reduce this. Psychotic symptoms at baseline were reported to describe the sample.

Illness Perceptions

A modified version of the Brief Illness Perception Questionnaire (M-BIPQ) was used to assess participants' self-reported illness perceptions of their mental health (appendix B). The original BIPQ was designed to rapidly assess cognitive and emotional representations of illness in clinical populations, large research studies, and with repeated follow-up (Broadbent, Petrie, Main, & Weinman, 2006). It was a shorter version

of the IPQ-R (Moss-Morris et al., 2002) and was developed by devising one question which best summarised each of the subscales. Five of the questionnaire items assess cognitive illness representations: consequences (Item 1), timeline (acute-chronic; Item 2), personal control (Item 3), identity (Item 4), and treatment control (Item 8). Two of the items assess emotional illness representations: concern (Item 5) and emotions (Item 7). One item represents illness comprehensibility (Item 6). Responses on these items were rated using a 10-point Likert scale (0 – 10). The question assessing causal beliefs was not used in analyses due to the variability of responses and difficulty interpreting the meaning of individual responses. This is in line with previous studies (Lobban et al., 2004; Marcus et al., 2014; Watson et al., 2006). All questions were rated on an 11-point Likert scale, positively framed questions were reverse scored (items 3, 6, 8, 9, and 10). Higher scores indicate more negative/less adaptive illness perceptions, for instance, that mental health problems have a severe impact on life, will continue for a long time, are uncontrollable, not understandable, extremely concerning and emotionally affecting, and that treatment will not be helpful (Table 2.1).

The original BIPQ was found to have good test-retest reliability and concurrent, predictive and discriminant validity (Broadbent et al., 2006). The psychometric properties of the BIPQ were further assessed using meta-analyses across a wide range of ages, illness types and countries. It was found to have good concurrent and predictive validity, as well as sensitivity to change during interventions and over time when using single item scales (Broadbent et al., 2015). While internal reliability cannot be assessed for single item measures, acceptable reliability could be assessed based on convergent validation measures which can be more robust than scale measures of an overall construct (Wanous, Reichers, & Hudy, 1997). The BIPQ has previously been used with in psychosis and bipolar (Etain et al., 2018; Lobban et al., 2013; Maguire, Reay, & Raphael, 2016; Proudfoot et al., 2012).

Several modifications were made to the BIPQ to make it appropriate for use in psychosis and the service context. Wording alterations included: 'illness' referred to as 'mental health problems' and 'treatment' referred to as 'talking therapy'. Two items (drawn from the talking therapies outcome literature and previously piloted by Marcus et al., 2014) were added to assess expectations of change and the extent to which a cognitive behavioural approach fitted with an individual's own ideas about what would help with their problems (Items 9 and 10). A previous exploratory factor analysis indicated the total score of the modified B-IPQ has poor psychometric properties with low internal consistency (Cronbach's a = 0.579) and some collinearity amongst the items, with multiple inter-item correlations of 0.3 or above, (Grant, 2016). Therefore, the validity of using the total score in the present study was further assessed.

Psychological Distress

Psychological distress was assessed using the Clinical Outcomes in Routine Evaluation (CORE-10 (Barkham et al., 2013). This measure is a ten item self-report questionnaire which generates a total distress score ranging from 0 (low levels of distress) to 40 (severe levels of distress) based on each item

being rated on a 5-point Likert scale from 0 to 4 (appendix C). It was developed as a short measure to be used clinically to assess levels of distress during psychological therapies. It showed good psychometric properties with internal reliability (alpha) of .90. The clinical cut-off for general psychological distress is 11.0 with a reliable change index (90% CI) of 6. Scores were used in analyses for this study as continuous outcome data.

Psychosis Symptoms

The Psychotic Symptom Rating Scales (PSYRATS; Haddock, McCarron, Tarrier, & Faragher, 1999) was used to assess current positive symptoms, specifically subjective characteristics of hallucinations and delusions (appendix D). It consists of two semi structured interviews designed to elicit whether individuals experienced any relevant symptoms, providing more detailed information than global symptom scales and detecting symptoms in those who may not report them spontaneously. For those reporting no relevant symptoms on the first question, the rest of interview was not completed and given a score of zero. The auditory hallucinations subscale has 11 items assessing the frequency, duration, location, loudness, beliefs about the origin of voices, amount and degree of negative content, severity and intensity of distress, controllability and the disruption to life caused by voices. The distressing beliefs subscale has six items assessing the amount, duration and conviction of preoccupation with beliefs, the amount and intensity of distress and disruption to life caused by beliefs. Each item asked for a response on a scale from 0 (absent) to 4 (severe). Total scores for each subscale were calculated with higher scores reflecting greater psychopathology. The rating scales were found to have good psychometric properties, including good inter-rater reliability and retest reliability, and good validity in relation to internal consistency, sensitivity to change and concurrent (Drake, Haddock, Tarrier, Bentall, & Lewis, 2007; Woodward et al., 2014).

Engagement

Engagement was estimated using a proxy measure of number of sessions attended. Participants who attended four or fewer sessions were considered to have not engaged in therapy and those who attended five or more sessions were considered to have engaged in therapy. This cut-off has been used in previous studies assessing CBTp in similar services (Johns et al., 2019). The possibility of a non-linear relationship was assessed using three categories of engagement, based on number of sessions from a previous study (Garety et al., 2008), full therapy (12 or more sessions), partial therapy of between (5 - 11 sessions) and no therapy (0 - 4 sessions).

Service User Involvement

Service users were consulted in this project in two ways. The proposal was assessed by The NIHR Maudsley Biomedical Research Centre (BRC) service to researchers called FAST-R (Feasibility and Acceptability Support Team for Researchers). The Peer Recovery Lead at PICuP was also consulted to gain their

perspective, insights and advice. They were approached for consultation as they were already familiar with the service and its functions and were well supported in their role. Their perspective was based on their own experience of CBTp at PICuP and also the perspectives of other service users they had supported and had conversations with as part of their role. Two meetings were scheduled with the following aims:

1. To discuss the proposal, including:
    a. The concept of illness perceptions in the context of CBTp
    b. How illness perceptions may interact with levels of distress during the process of therapy
    c. The design of the study
    d. The measurement of what we are investigating, e.g. how to capture/measure "engagement" in CBTp.
2. To discuss the findings, including:
    a. Interpretation of findings
    b. Clinical implications

Service user perspectives arising from these discussions were considered throughout the research process. For example, the real world relevance and meaningfulness of the aims and hypotheses to those that have lived experience of CBTp. The issues that were highlighted related to using number of sessions attended as a proxy for engagement informed decision making about how to conceptualise engagement. Additionally, the meaning and interpretation of the findings were considered in relation to service user perspectives when making inference from the results and writing the discussion.

Ethics

Ethical approval was granted by the London-Dulwich Research Ethics Committee for the use of the clinical database for research purposes (15/LO/1831). Copies of approval documentation are included in appendix E.

Data analysis

Hypothesis 1: More positive or adaptive illness perceptions prior to starting therapy will predict better engagement

Engagement was operationalised according to national Improving Access to Psychological Therapies for Severe Mental Illness (IAPT-SMI) criteria (Johns et al., 2019): fewer than five sessions of therapy as did not engage and five or more sessions of therapy as did engage. Tests of difference were carried out between those who engaged in therapy and those who did not engage, t-tests for continuous data and chi-square tests for categorical data. The possibility of a non-linear relationship between engagement and dimensions of illness perceptions was assessed using three categories of number of sessions based on

previous study (Garety et al., 2008), full therapy (12 or more sessions), partial therapy of between (5 - 11 sessions) and no therapy (0 - 4 sessions), using a chi-square test.

Hypothesis 2: Change to more positive or adaptive illness perceptions during CBTp will be associated with a reduction in psychological distress during therapy.

Paired t-tests were used to assess for change from pre- to post-therapy across dimensions of illness perceptions and distress. Pearson's correlations were used to assess the relationships between each dimension of illness perception and levels of distress at each time point. Pearson's correlations were also used to assess relationships between each dimension of illness perception and levels of distress between pre- and mid-therapy and between mid- and post-therapy time points. Effect sizes for correlations were considered large if > 0.5, medium if around 0.3 and small if around 0.1 (Cohen, 2013).

Structural Equation modelling (SEM)

SEM is a multivariate technique which combines measurement model and multiple regression analysis. It assesses relationships between measured variables and latent constructs. Measured variables are directly observed, for example, scores on a questionnaire. Latent variables (factors), are not directly measured but represent a construct that questionnaire items represent, for example, levels of distress. Figure 2.1 shows an example confirmatory factor analysis (CFA), which is a type of measurement model which includes a latent factor, observed variables, and single headed arrows running to the latent factor which represent factor loadings in factor analyses. A structural model assesses the relationships between constructs. There are two types of variables in SEM, endogenous and exogenous. Exogenous variables are equivalent for the independent variable and endogenous variables are equivalent to dependent variables. A linear and causal relationship is assumed, whereby exogenous variables occur before endogenous variables.

Goodness of fit indices

Model fit was assessed for all SEM analyses using Root Mean Square Error of Approximation (RMSEA), Tucker Lewis Index (TLI), Comparative Fit Index (CFI) and Standardised Root Mean Square Residual (SRMR). To indicate good model fit the RMSEA value should be less than 0.06 (adequate fit close to or below 0.08) with upper confidence interval (CI) of less than 0.1, TLI and CFI values close to or greater than 0.95 (adequate fit > 0.90), and SRMR should be less than or equal to 0.08. (Hu & Bentler, 1999). The Chi-square goodness of fit indication was not used as it depends on sample size, with large samples resulting in rejecting models of good fit based on significance level ($p < 0.05$) (Bentler & Bonett, 1980).

Table 2.1 Item model dimensions, questions and response ratings on modified version of the BIPQ

Item No.	Model dimension	Question	Response rating anchors 0 - 10
1	Consequences (effect of illness on life)	How much do you think mental health problems affect your life?	No affect at all - severely affects my life
2	Timeline (expected duration of illness)	How long do you think your mental health problems will continue?	A very short time - forever
3	Personal control	How much control do you feel you have over your mental health problems (that is, how easy would it be for them to improve by your own efforts)?	Absolutely no control - total control
4	Identity (symptoms of illness)	How much do you experience 'symptoms' from your mental health problems?	No symptoms at all - many severe symptoms
5	Concern	How concerned are you about your mental health problems?	Not at all concerned - extremely concerned
6	Coherence: understanding of illness	How well do you feel you understand your mental health problems?	Don't understand at all - understand very clearly
7	Emotional reaction	How much do your mental health problems affect you emotionally (e.g. does it make you angry, scared, upset or depressed)?	Not at all emotionally affected - extremely emotionally affected
8	Treatment control	How much do you think talking therapy can help with your mental health problems?	Not at all - extremely helpful
9	*Items added to assess expectations of change and whether CBT approach fits with beliefs*	How much do you think changing the way you think or the way you do things can improve your mental health problems?	Not at all - extremely
10		How much do you think looking at things differently can be helpful?	Not at all - extremely

Note: Response ratings for items 3, 6, 8, 9, 10 were reversed prior to analyses.

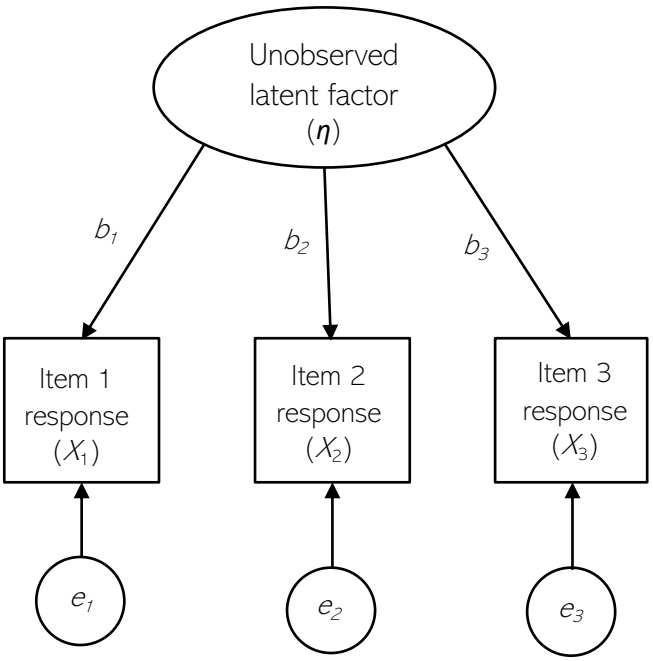

Figure 2.1 Example of a confirmatory factor analysis where η = the latent continuous construct, b = item loadings onto factor, X = response on a questionnaire item, and e = error

Assessing the validity of latent factors

It is necessary to assess the validity of latent factors prior to performing SEM. CFAs were carried out for both the CORE-10 and modified BIPQ. The factor analysis for the CORE-10 showed good model fit for one latent factor indicating it was representing a single factor of level of distress (CFI = 0.97, TLI = 0.97, RMSEA = 0.05 90% CI = 0.02-0.07, SRMR = 0.04). The total score for the modified version of the BIPQ showed poor psychometric properties when assessed previously in an Exploratory Factor Analysis (EFA) (Grant, 2016). There was poor internal consistency (Cronbach's a = 0.579), collinearity (multiple inter-item correlations above 0.3), and data appeared to fit three factors rather than one. A CFA was carried out to further assess the suitability of using the total score in the present sample. This was carried out for both the total score and the three factors found in the previous EFA: Impact (items 1, 2, 4, 5, 7), Control and Understanding (items 3 and 6) and Psychological change (items 8, 9 10). The CFA of the modified BIPQ measure indicated poor fit (CFI = 0.5, TLI = 0.37, RMSEA = 0.22, SRMR = 0.16). The relative goodness of fit between measurement models was assessed using the Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC) which indicated that the CFA with three factors was superior to the total score model. This was further assessed using a Chi-square test which indicated the model fit was significantly superior for the three factor model compared to the total score model. However, the factors that emerged in the exploratory factor analysis were not used as subscales in analysis of the present study as one factor consisted of only two items and a minimum of three are needed to make up a latent variable. Additionally, these subscales had not been used in other studies and therefore findings would not be comparable. Individual items for the BIPQ have been used in analysis of previous studies and found variation in relationships with outcomes, therefore it was important for the present study to investigate

them separately. Phantom latent variables were created for SEM analysis for each modified BIPQ item so that measurement error estimates could be calculated and included in the model.

Cross Lagged Panel Models

Cross Lagged Panel Models (CLPM) were used to test hypotheses 2. They are a type of longitudinal structural equation modelling (SEM) that can be used when two or more variables are measured at two or more time points to investigate associations between variables over time. It is often used to test hypotheses about causal directionality (Newsom, 2015). Regression analyses allow for single cross lagged effects to be tested but with SEM both directional hypotheses can be tested in the same model. This is appropriate for the present study due to limited previous longitudinal research in this area and indication that the direction of the effect could that illness perceptions predict distress outcomes and vice versa (Berk et al., 2013; Lobban et al., 2004). If the cross lagged effect is significant in one direction but not the other then this would indicate that the causal effect is present in one direction but not the other. If neither of the cross lagged paths are significant then this would indicate that there is no causal effect in either direction within the study time frame and sample size. If both of the cross lagged paths are significant then this would suggest that the causal effect works in both directions. Figure 2.2 shows an example CLPM with two latent factors across three time points. This structure was used in the present study and a proposed model is shown in figure 2.3. Double headed arrows indicate covariance and single headed arrows indicate direct regression paths. This allows causation to be assessed between dimensions of illness perceptions and levels of distress during therapy. Cross lagged effects between mid- and post-therapy can indicate whether change predicting outcome as endogenous are controlled for scores on measures from previous time points. For example, if the cross lagged path from mid-therapy illness perceptions to post-therapy level of distress is significant then this indicates that change in illness perceptions predicts levels of distress. Standardised estimates were obtained from analyses to enable comparisons of effect sizes. Figure 2.3 shows the proposed model to test Hypothesis 2. Full measurement models and error estimates were omitted from the CLPM path diagrams presented in the results section for clarity as they were not central to hypothesis testing.

Longitudinal measurement invariance

It is routine procedure to investigate measurement invariance when running SEM. It can be appropriate to assess it between groups, however in this study it was appropriate to assess across time points. The Likelihood ratio test was used to compare CLPMs model fit when item loadings were free to vary versus when they were constrained (metric invariance). Constraints were added to each item loading to the latent factor so that they were consistent at each time point, for instance, item 1 at pre-, mid-, and post-therapy. This test indicated that model fit did not decrease with loading constraints added, therefore these were applied to all CLPMs.

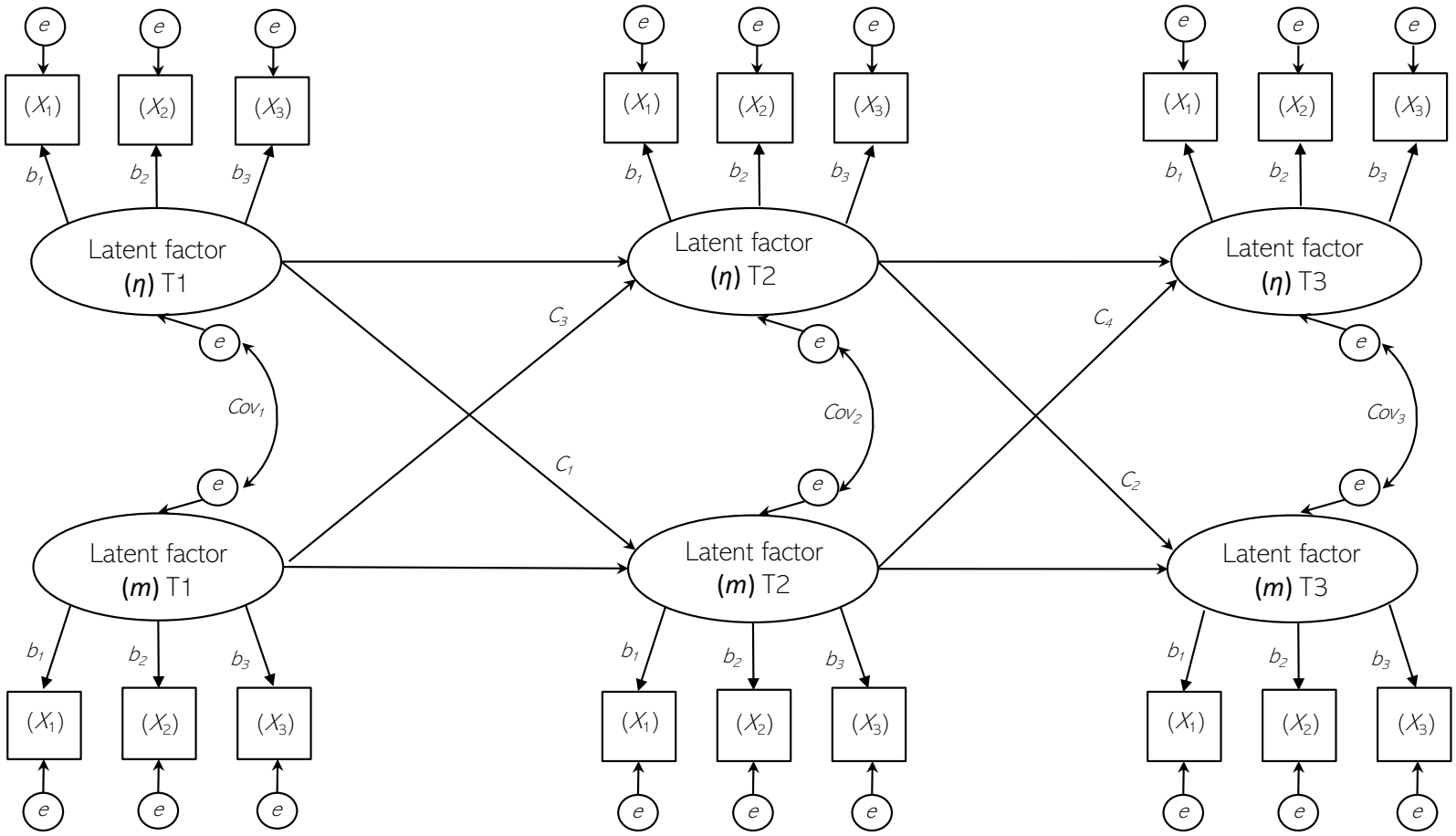

Figure 2.2 Represents a cross lagged panel model for three waves of data with two latent factors

η = one latent continuous construct, m = a second latent continuous construct, b = item loadings onto factor, X = response on a questionnaire item, e = error, T1 = pre-therapy, T2 = mid-therapy, T3 = post-therapy, Cov = covariance path between variables, C = cross lagged path.

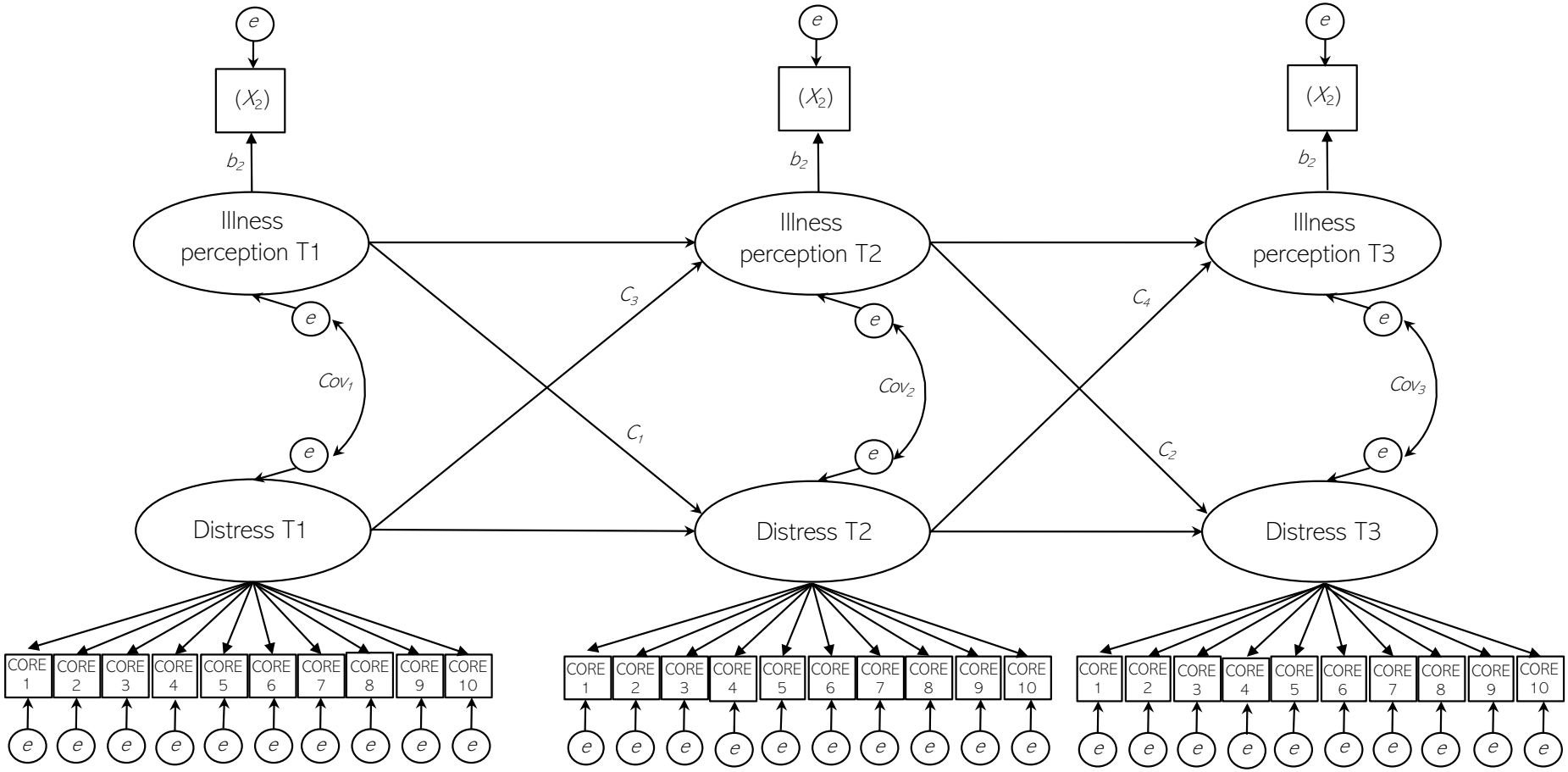

Figure 2.3 Proposed cross lagged panel model to assess hypothesis 2.

X = response on modified BIPQ questionnaire item, *e* = error, T1 = pre-therapy, T2 = mid-therapy, T3 = post-therapy, *Cov* = covariance path between variables, *C* = cross lagged path.

Missing data

Data missing of measure items

Missing data on questionnaire items for the CORE-10 and Modified BIPQ were assessed using Little's Missing Completely at Random (MCAR) test. Data on these measures were found to be missing at random at all time points. Mean imputation to two decimal place was carried out for those that had 30% or less items missing, based on participants other item scores for that measure at that timepoint (Eekhout et al., 2014). Approximately 2.8% of measures had 10% of items missing, approximately 0.01% had 20% missing and less than 0.001% had 30% missing.

Data missing at timepoints

To minimise the exclusion of data collected and maximise the likelihood of representing the sample, participants were required to have completed both the CORE-10 and the Modified BIPQ on at least two time points to be included in analyses. These two time points could be any of the three pre-, mid- or post-therapy assessments. This left 248 participants in the sample for analysis out of a potential 543 since the modified BIPQ was added to the routine clinical assessment. There was a proportion of mid-therapy modified BIPQ data missing due to a period of staff shortage in the service resulting in assessments not being administered. Missing total scores for the CORE-10 and modified BIPQ across time points were assessed using the MCAR test and indicated that the pattern of missingness was random.

The maximum likelihood estimation was used to deal with data missing at timepoints in CLPM analyses to allow for all available information in the variables to be used. It works by estimating a likelihood function for each individual based on the data available from variable at other time points. It has been shown to produce unbiased estimates and standard errors for data missing completely at random (Dee & Da Silva, 1999).

Normal distributions

Where visual inspection of data indicated non-normality of distribution, bootstrapping with 2000 samples was applied.

Multiple comparisons

Analyses in the present study included multiple comparisons. To reduce likelihood for Type 1 error, findings were primarily reported in relation to effect sizes rather than significance levels.

Statistical software

Structural equation modelling (SEM) was carried in R 3.6 (R Core Team, 2017), using R package lavaan (Rosseel, 2012) other analyses were carried out in SPSS 26.0.

RESULTS

Participant characteristics

The total number of participants with sufficient data for inclusion in analyses was 351. Sample characteristics are presented in table 2.2 split by those who engaged in therapy (five or more sessions) and those who did not (4 or fewer sessions), and also separately for those that had sufficient data to be included in the longitudinal SEM analysis. Those who engaged in therapy did not differ from those who did not engage in therapy in age (t = -1.57, p = 0.12), gender (X^2 = 0.02, p = 0.90), ethnicity (X^2 = 2.55, p = 0.11), baseline levels of distress (t = -0.93, p = 0.36) and baseline severity of delusional beliefs (t = 0.97, p = 0.29). However, those who engaged in therapy did report lower severity of hearing voices at baseline compared to those who did not engage (t = 2.07, p = 0.016).

Hypothesis 1: More positive or adaptive illness perceptions prior to starting therapy will predict better engagement

Baseline illness perceptions across all dimensions for those who engaged in therapy and those who did not are included in table 2.2. There were significant differences in two dimensions of illness perceptions at baseline between those engaged or did not engage in CBTp. Those who engaged in therapy had significantly lower perceptions of personal control (t = -2.06, p = 0.01) compared to those who did not engage. Those who engaged in therapy had higher perceptions that talking therapy would be helpful (t = 2.68, p = 0.02) compared than those who did not engage. There were no significant differences in other dimensions of illness perceptions (p > 0.05).

There did not appear to be a non-linear relationship with personal or treatment control and engagement in therapy divided into three categories of number of sessions, full therapy (12 or more sessions), partial therapy of between (5 - 11 sessions) and no therapy (0 - 4 sessions). Those who engaged in full therapy had lower perceptions of personal control (mean = 5.47) compared to both those who engaged in partial (mean = 4.98) or no therapy (mean = 4.26), Those who engaged in full therapy had higher perceptions of treatment control (mean = 1.97) compared to both those who engaged in partial (mean = 2.19) or no therapy (mean = 2.87).

Mean scores of other illness perception dimensions across the three engagement categories indicated that there may be some non-linear relationships for: consequences, timeline, identity, coherence, changing the way you think/do things can improve mental health. However, these differences were not significant (see appendix F). Severity of symptoms appeared to be associated with engagement, whereby those who did not engage in therapy had significantly higher severity of voice hearing pre-therapy compared to those who did engage. Severity of delusions beliefs was not associated with engagement in therapy.

Table 2.2 Sample characteristics

	Hypothesis 1: Engagement analysis (n = 351)		Hypothesis 2 analysis (n = 248)
	Non engagers	Engagers	
n	46	305	248
Age, mean (SD) range	39.4 (9.7) 24-66	42.0 (10.5) 18-64	41.9 (10.4) 18-66
gender	52% female	53% female	52% female
Ethnic group			
Black/Minority Ethnic (BME)	57%	45%	42%
Non BME	42%	55%	54%
Diagnosis			
Schizophrenia spectrum	65%	67%	64%
Bipolar	12%	11%	13%
Psychotic depression	18%	12%	12%
Other	6%	9%	5%
Baseline symptoms			
PSYRATS-Voices	28.8	21.6*	22.0
PSYRATS-Delusional beliefs	15.1	12.9	13.1
Baseline distress			
CORE	16.5	17.7	17.4
Baseline illness perceptions			
Consequences	6.98	7.16	7.18
Timeline	6.89	7.06	6.97
Personal control	4.26	5.39*	5.43
Identity	6.41	6.48	6.35
Concern	7.07	7.86	7.89
Coherence	4.20	4.23	4.32
Emotional reaction	7.04	7.69	7.68
Treatment control	2.87	2.10*	1.89
Changing the way think/do things to improve mental health	2.42	2.43	2.38
Looking at things differently is helpful	2.44	2.12	2.09

Means presented for continuous data. Significant difference between groups chi square for categorial data or t-tests for continuous data *$p < 0.05$; SD = standard deviation

Hypothesis 2: Change to more positive or adaptive illness perceptions during CBTp will be associated with a reduction psychological distress during therapy.

A subsample of participants (n = 248) had sufficient data to be included in analysis to assess the relationship between illness perceptions and distress outcome in therapy. Participant characteristics for this subsample are included in Table 2.2.

Change during therapy

Mean scores and standard deviations for each illness perception dimension and distress across pre-, mid-, and post-therapy time points are included in table 2.3. Level of distress significantly reduced during

therapy ($t = 9.34$, $p < 0.001$). The majority of illness perceptions dimensions became significantly more positive/adaptive during therapy, including: consequences ($t = 8.82$, $p < 0.001$), timeline ($t = 3.06$, $p = 0.003$), personal control ($t = 7.54$, $p < 0.001$), identity ($t = 5.33$, $p < 0.001$), concern ($t = 8.06$, $p < 0.001$), coherence ($t = 8.84$, $p < 0.001$), emotional response ($t = 8.38$, $p < 0.001$), and treatment control ($t = 3.04$, $p < 0.001$). However, perceptions that changing the way the way you think or do things can improve mental health ($t = 0.87$, $p = 0.384$) and how much looking at things differently as helpful ($t = -0.18$, $p = 0.856$) did not significantly change.

Table 2.3 Mean scores and standard deviations for illness perceptions and distress across time points

Measure	Mean score (standard deviation)		
	Pre-therapy	Mid-therapy	Post-therapy
1. Consequences	7.18 (2.47)	6.32 (2.76)	5.44 (2.88)***
2. Timeline	6.97 (2.78)	6.56 (2.82)	6.30 (3.28)**
3. Personal control	5.43 (2.79)	4.75 (2.58)	3.81 (2.39)***
4. Identity	6.35 (2.66)	5.80 (2.80)	5.22 (3.06)***
5. Concern	7.89 (2.24)	6.80 (2.77)	6.20 (3.09)***
6. Coherence	4.23 (2.26)	3.73 (2.55)	2.45 (2.15)***
7. Emotional response	7.68 (2.15)	6.80 (2.66)	5.83 (3.08)***
8. Treatment control	1.89 (1.93)	1.76 (1.86)	1.42 (1.75)**
9. Changing the way think/do things to improve mental health	2.38 (2.26)	2.44 (2.30)	2.17 (2.16)
10. Looking at things differently as helpful	2.09 (2.13)	2.29 (2.30)	2.13 (2.11)
CORE-10	17.44 (7.97)	15.08 (7.54)	11.97 (8.16)***

*p = or < 0.05, ** p = or < 0.01, ***p = or < 0.001

Correlations

Correlations between dimensions of illness perceptions and levels of distress at each time point and correlations of cross lagged paths are presented in Table 2.4. Overall, correlations between dimensions of illness perceptions and levels of distress appeared to increase in effect size towards the end of therapy for consequences, concern, coherence, emotional response, treatment control, changing the way think/do things and looking at things differently. Correlations remained stable for perceptions of personal control and decreased for perceptions of timeline.

Pre-therapy correlations

Pre-therapy, correlations with large effect sizes were found for consequences, identity, personal control, emotional response, and timeline. Correlations with small to medium effect sizes were found for concern

and changing the way think/do things and looking at things differently as helpful. The correlations was not significant for timeline.

Mid-therapy correlations

Mid-therapy, correlations with large effect sizes were found for consequences, identity, emotional response, personal control, and concern. Medium effect sizes were found for timeline, coherence, and looking at things differently as helpful. Small effect sizes were found for treatment control and changing the way think/do things.

Post therapy correlations

Mid-therapy, correlations with large effect sizes were found for consequences, emotional response, identity, personal control, concern, looking at things differently as helpful, and changing the way think/do things. Medium effect sizes were found for timeline, coherence, and treatment control.

Cross lagged correlations

Correlations between cross lagged paths are reported in table 2.4. Correlations between pre-therapy illness perceptions and mid-therapy levels of distress were strongest for symptom identity, emotional response. and consequences. Correlations between mid-therapy illness perceptions and post-therapy levels of distress were strongest for symptom identity and consequences.

Correlations between pre-therapy levels of distress and mid-therapy illness perceptions were strongest for symptom identity, consequences, and emotional response. Correlations between mid-therapy levels of distress and post-therapy illness perceptions were strongest for consequences, symptom identity, concern, emotional response, and personal control.

Table 2.4 Correlations between dimension of illness perceptions (IP) and levels of distress at each time point and correlations of cross lagged paths

Illness perception dimension at corresponding time point	Correlations with level of distress (CORE-10 scores)			Correlations of cross lagged paths			
	Pre-therapy	Mid-therapy	Post-therapy	Pre IP → Mid distress	Mid IP → Post distress	Pre distress → Mid IP	Mid distress → Post IP
1. Consequences	0.61***	0.65***	0.70***	0.44***	0.48***	0.58***	0.55***
2. Timeline	0.46***	0.39***	0.30***	0.37***	0.26**	0.39***	0.26**
3. Personal control	0.53***	0.51***	0.52***	0.42***	0.27**	0.40***	0.47***
4. Identity	0.61***	0.62***	0.62***	0.53***	0.48***	0.56***	0.50***
5. Concern	0.41***	0.47***	0.60***	0.26***	0.34***	0.36***	0.50***
6. Coherence	0.18*	0.41***	0.41***	0.35***	0.37***	0.40***	0.31***
7. Emotional response	0.47***	0.60***	0.68***	0.45***	0.43***	0.55***	0.49***
8. Treatment control	0.04	0.22*	0.32***	0.09	0.17	0.09	0.20*
9. Changing the way think/do things to improve mental health	0.20**	0.22*	0.45***	0.23**	0.27**	0.20*	0.29***
10. Looking at things differently as helpful	0.15*	0.31***	0.45***	0.11	0.30***	0.28**	0.30***

*p = or < 0.05, ** p = or < 0.01, ***p = or < 0.001

Cross lagged panel models analyses

Cross lagged panel models are presented for each dimension of illness perception in figures 2.4-2.13 and cross lagged coefficients are presented in table 2.5. All models demonstrated good fit (Table 2.6). Overall, effects sizes were larger for cross lagged paths for levels of distress predicting change in illness perceptions compared to the cross lagged paths for illness perceptions predicting change in levels of distress.

Item 1: Perceptions of consequences

No cross lagged effects were found for perceptions of consequences. Pre-therapy perceptions of consequences did not predict change in levels of distress in the first half of therapy and change in perceptions of consequences before mid-therapy did not predict change in levels of distress throughout therapy. However, cross lagged effects were found for levels of distress. Pre-therapy levels of distress predicted change in perceptions of consequences during the first half of therapy and change in levels of distress before mid-therapy predicted change in perceptions of consequences throughout therapy. The effect size of the pre- to mid-therapy cross lagged path was larger. Covariance paths between perceptions of consequences and levels of distress showed large effect sizes throughout therapy.

Item 2: Perceptions of timeline

No cross lagged effects were found for perceptions of timeline. Pre-therapy perceptions of timeline did not predict change in levels of distress up to mid-therapy and change in perceptions of timeline in the first half of therapy did not predict change in levels of distress throughout therapy. There were also no cross lagged effects for levels of distress. Pre-therapy levels of distress did not predict change in perceptions of timeline in the first half of therapy and change in levels of distress up to mid-therapy did not predict change in perceptions of timeline throughout therapy. However, covariance paths between perceptions of timeline and levels of distress showed large effect sizes throughout therapy.

Item 3: Perceptions of personal control

No cross lagged effects were found for perceptions of personal control. Pre-therapy perceptions of personal control did not predict change in levels of distress during the first half of therapy and change in perceptions of personal control mid-therapy did not predict levels of distress during therapy. However, cross lagged effects were found for levels of distress. Pre-therapy levels of distress predicted change in perceptions of personal control up to mid-therapy and change in levels of distress in the first half of therapy predicted change in perceptions of personal control throughout therapy. The effect size of these cross lagged paths was stronger for the latter part of therapy. Covariance paths between perceptions of consequences and levels of distress showed large effect sizes which decreased slightly during therapy.

Item 4: Perceptions of symptoms identity

Cross lagged effects were found for symptoms identity. Pre-therapy perceptions of identity predicted change in levels of distress during the first part of therapy. The effect size for this path was larger compared to the path for change in perception of identity in the first half of therapy predicting change in levels of distress throughout therapy, which was not significant. Cross lagged effects were found for levels of distress. Pre-therapy levels of distress predicted change in perceptions of identity in the first part of therapy, this effect size for this path was stronger compared to the change in levels of distress up to mid-therapy predicted perceptions of identity throughout therapy, which was not significant. Covariance paths between perceptions of identity and levels of distress showed large effect sizes which decreased during therapy.

Item 5: Perceptions of concern

No cross lagged effects were found for perceptions of concern. Pre-therapy perceptions of concern did not predict change in levels of distress in the first part of therapy and change in perceptions of concern in the first part of therapy did not predict change in levels of distress during therapy. However, cross lagged effects were found for levels of distress. Pre-therapy levels of distress predicted change in perceptions of concern in the first part of therapy and change in level of distress in the first part of therapy predicted change in perceptions of concern throughout therapy. Both these paths had similar effect sizes. Covariance paths between perceptions of concern and levels of distress showed large effect sizes during therapy.

Item 6: Perceptions of coherence

No cross lagged effects were found for perceptions of coherence. Pre-therapy perceptions of coherence did not predict change in levels of distress in the first part of therapy and change in perceptions of coherence in the first part of therapy did not predict change in levels of distress throughout therapy. Cross lagged effects were found for levels of distress. The effect size was larger for pre-therapy levels of distress which predicted change in perceptions of coherence during the first part of therapy, the path for change in levels of distress predicting change in perceptions of coherence throughout therapy was not significant. Covariance paths between perceptions of coherence and levels of distress showed medium effect sizes during therapy.

Item 7: Perceptions of emotional response

No cross lagged effects were found for perceptions of emotional response. Pre-therapy perceptions of emotional response did not predict change in levels of distress during the first part of therapy and change in perceptions of emotional response during the first part of therapy did not predict levels of distress throughout therapy. However, a cross lagged effect was found for levels of distress. Pre-therapy levels of distress predicted change in perceptions of emotional response during the first part of therapy with a larger effect size than the path for change in levels of distress predicting change in perceptions of emotional

response throughout therapy, which was not significant. Covariance paths between perceptions of emotional response and levels of distress showed large effect sizes during therapy.

Item 8: Perceptions of treatment control

No cross lagged effects were found for perceptions of treatment control. Pre-therapy perceptions of treatment control did not predict change in levels of distress in the first part of therapy and change in perceptions of treatment control during the first part of therapy did not predict change in levels of distress throughout therapy. There was a small cross lagged effect for pre-therapy levels of distress predicting change in perceptions of treatment control during the first part of therapy which approached significance. There was no cross lagged effect for change in levels of distress in the first part of therapy predicting change in perceptions of treatment control throughout therapy. Covariance paths between perceptions of treatment control and levels of distress increased in effect size during therapy, after no association pre-therapy.

Item 9: Perceptions of changing the way you think or do things can improve mental health

There were cross lagged effects for perceptions of changing the way you think or do things can improve mental health. Pre-therapy perceptions of changing the way think or do things as helpful did not predict change in levels of distress in the first part of therapy, however change in these perceptions during the first part of therapy predict change in levels of distress throughout therapy. There were cross lagged effects for levels of distress. The effect size was larger for change in levels of distress in the first part of therapy predicting change in perceptions of changing the way you think/do things as helpful throughout therapy compared to pre therapy levels of distress predicting change in perceptions of changing the way you think/do things during the first part of therapy. Covariance paths between these perceptions and levels of distress increased in effect size from pre- to post-therapy, but showed no association at mid-therapy.

Item 10: Perceptions of looking at things differently as helpful

A cross lagged effect was found for perceptions of looking at things differently as helpful. Change in perceptions of looking at things differently as helpful in the first part of therapy predicted change in levels of distress throughout therapy, this path approached significance. There was no effect for pre-therapy perceptions of looking at things differently as helpful did not predict change in levels of distress during the first part of therapy. Cross lagged effects were found for levels of distress. The effect size was stronger for pre-therapy levels of distress, which predicted change in perceptions of looking at things differently as helpful during the first part of therapy. The effect for change in levels of distress predicting change in perceptions looking at things differently as helpful throughout therapy was trend significant. Covariance paths between perceptions of looking at things differently as helpful and levels of distress increased considerably in effect size during therapy.

Table 2.5 Cross lagged regression path coefficients for each illness perception dimension

Illness perception dimension	Cross lagged regression path coefficients			
	Pre IP → Mid distress	Mid IP → Post distress	Pre distress → Mid IP	Mid distress → Post IP
1. Consequences	-0.007	0.042	0.347***	0.277*
2. Timeline	0.000	0.013	0.083	-0.036
3. Personal control	0.018	-0.091	0.261**	0.463***
4. Identity	0.171**	0.107	0.331***	0.229
5. Concern	-0.069	-0.001	0.237**	0.240*
6. Coherence	0.060	0.064	0.302***	0.131
7. Emotional response	-0.075	0.000	0.360***	0.150
8. Treatment control	0.053	0.050	0.129	0.034
9. Changing the way think/do things can improve mental health	0.081	0.182*	0.132	0.200*
10. Looking at things differently as helpful	-0.014	0.134	0.218**	0.139

*p = or < 0.05, ** p = or < 0.01, ***p = or < 0.001

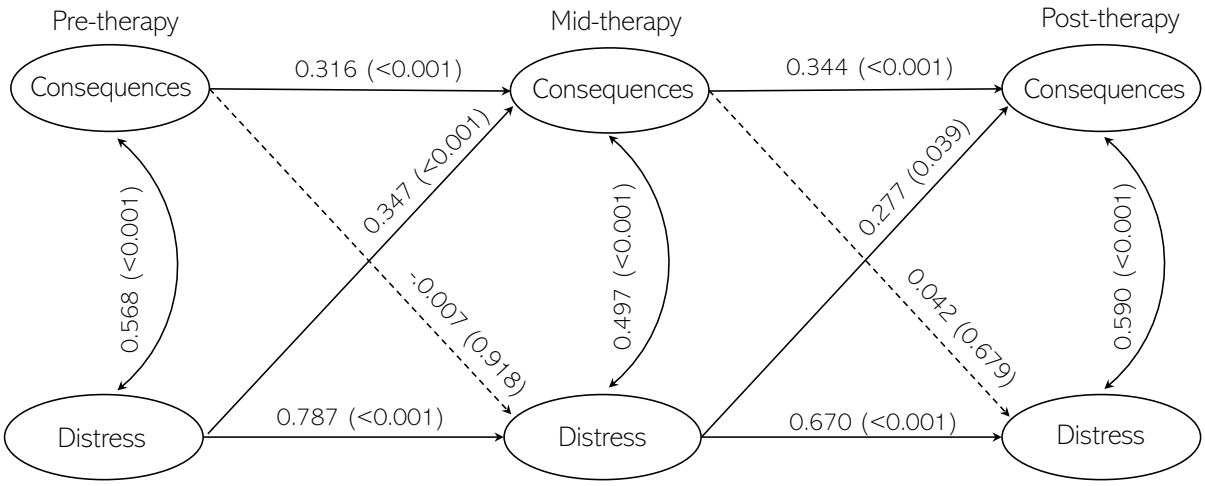

Figure 2.4 Cross lagged panel model for perceptions of consequences and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (p values) are presented.

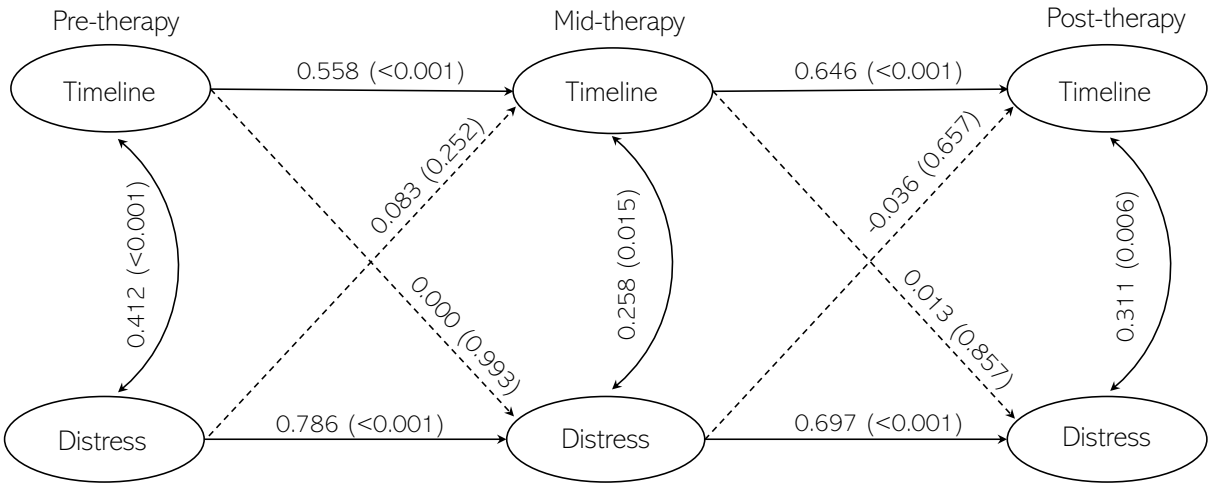

Figure 2.5 Cross lagged panel model for perceptions of timeline and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (*p* values) are presented.

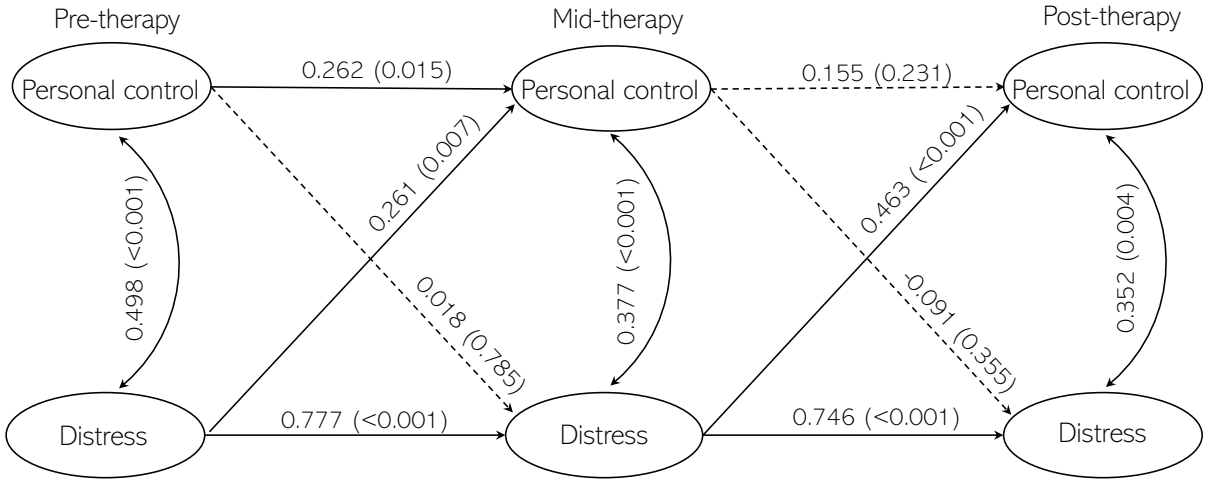

Figure 2.6 Cross lagged panel model for perceptions of personal control and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (*p* values) are presented.

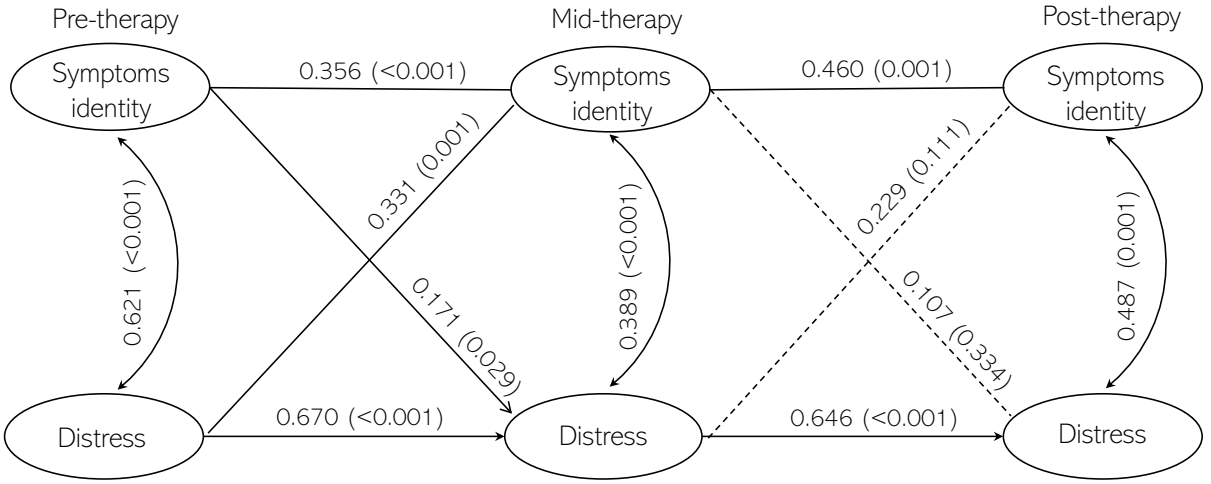

Figure 2.7 Cross lagged panel model for perceptions of symptoms identity and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (*p* values) are presented.

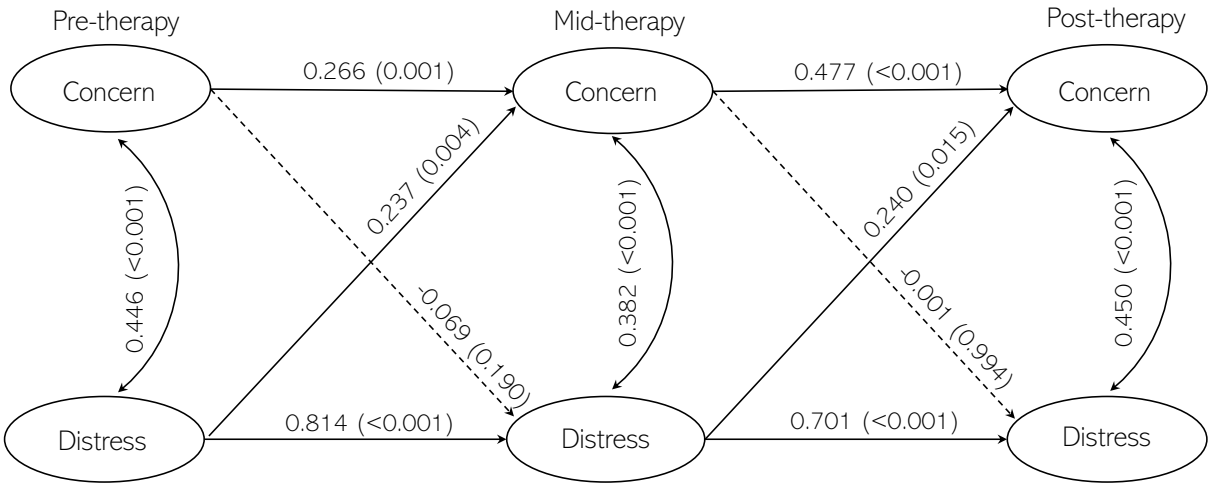

Figure 2.8 Cross lagged panel model for perceptions of concern and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (p values) are presented.

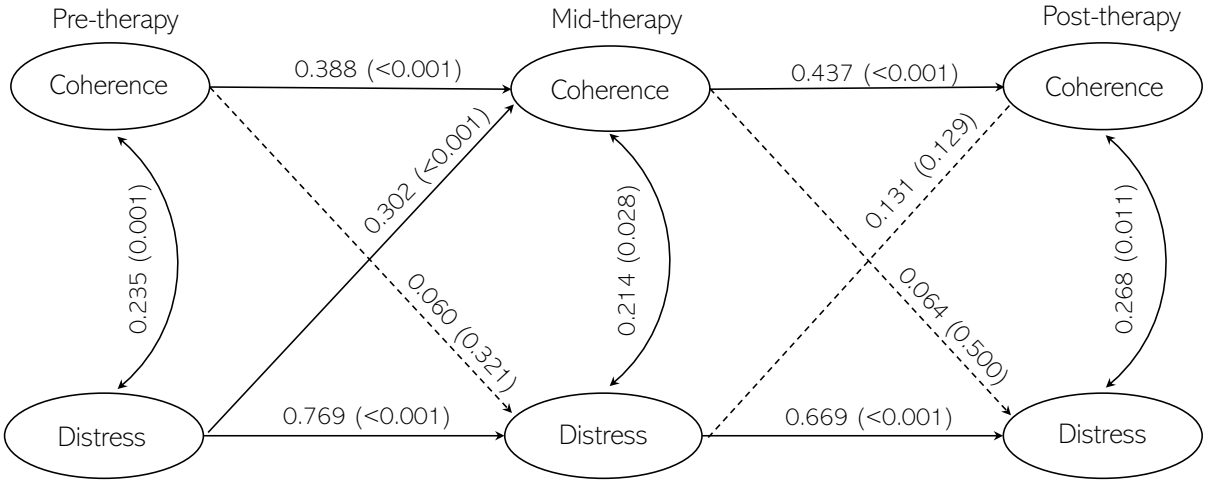

Figure 2.9 Cross lagged panel model for perceptions of coherence and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (p values) are presented.

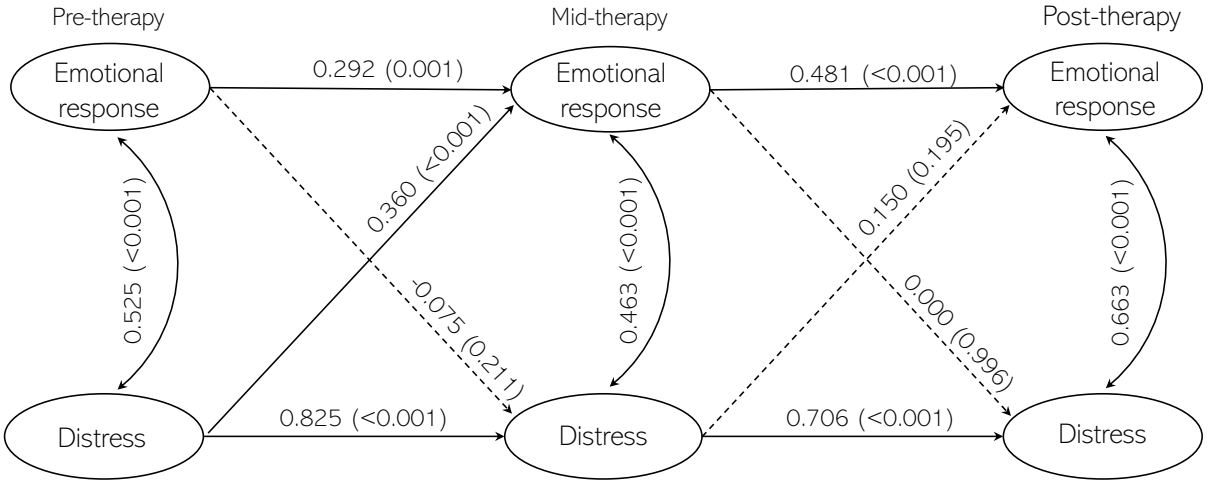

Figure 2.10 Cross lagged panel model for perceptions of emotional response and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (p values) are presented.

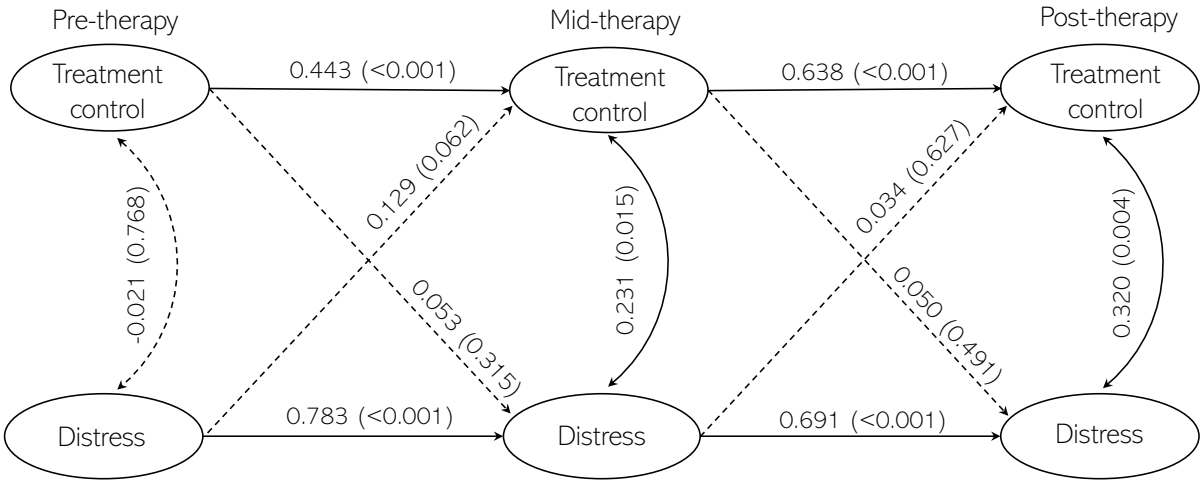

Figure 2.11 Cross lagged panel model for perceptions of treatment control and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (*p* values) are presented.

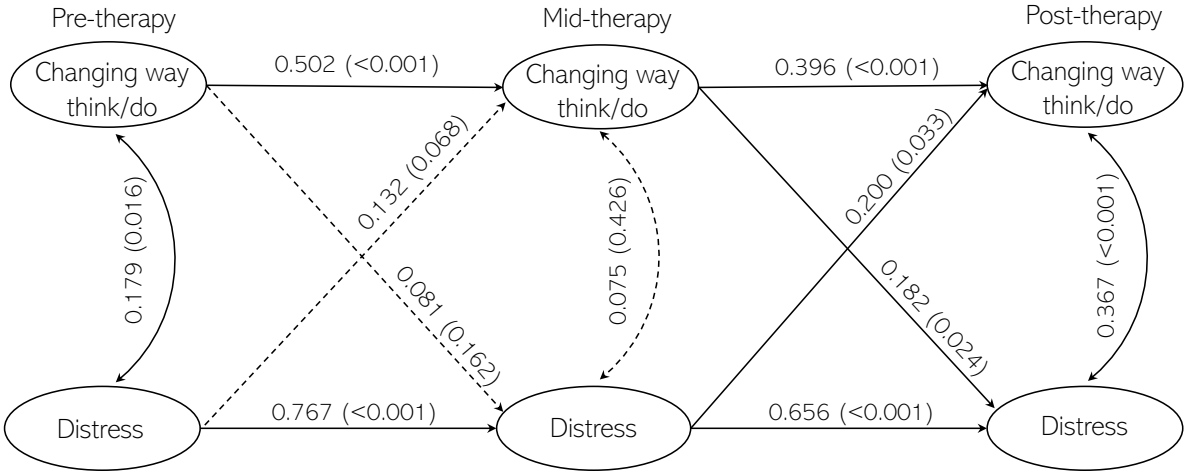

Figure 2.12 Cross lagged panel model for perceptions of changing the way you think/do things can improve your mental health and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (*p* values) are presented.

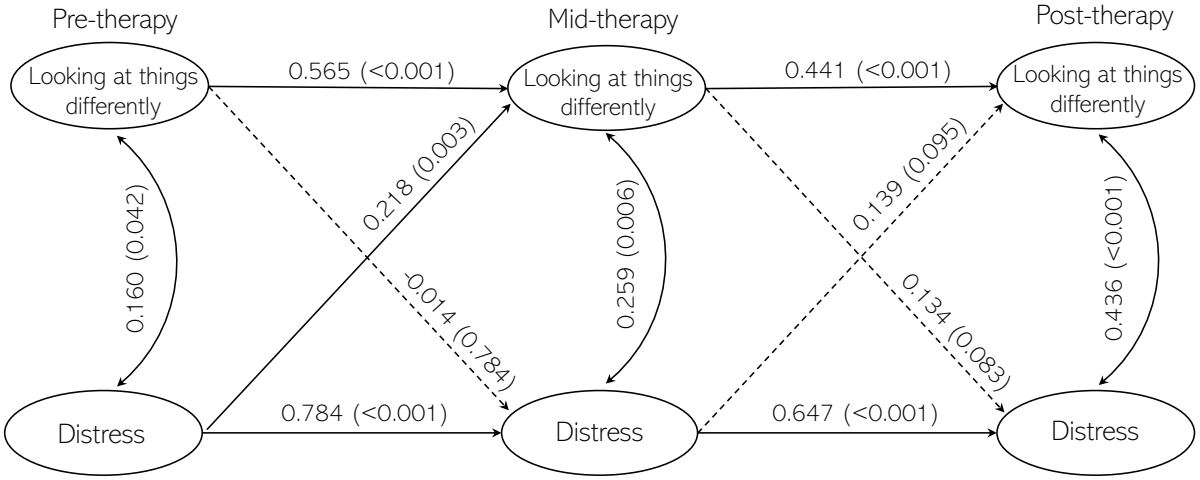

Figure 2.13 Cross lagged panel model for perceptions of looking at this differently as helpful and level of distress pre-, mid- and post-therapy. Standardized regression coefficients and covariances (*p* values) are presented.

Table 2.6 Model fit indices for all cross lagged panel models

Illness perception dimension	Model fit indices			
	RMSEA (90% CI)	TLI	CFI	SRMR
1. Consequences	0.04 (0.04-0.05)	0.92	0.93	0.06
2. Timeline	0.04 (0.04-0.05)	0.93	0.93	0.06
3. Personal control	0.04 (0.03-0.05)	0.93	0.94	0.06
4. Identity	0.04 (0.04-0.05)	0.93	0.93	0.06
5. Concern	0.04 (0.03-0.05)	0.93	0.94	0.06
6. Coherence	0.05 (0.04-0.05)	0.92	0.92	0.06
7. Emotional response	0.04 (0.03-0.05)	0.93	0.94	0.06
8. Treatment control	0.04 (0.04-0.05)	0.92	0.93	0.06
9. Changing the way think/do things to improve mental health	0.05 (0.04-0.05)	0.91	0.92	0.06
10. Looking at things differently as helpful	0.05 (0.04-0.05)	0.91	0.92	0.06

CI = confidence intervals; RMSEA = Root Mean Square Error of Approximation; TLI = Tucker Lewis Index; CFI = Comparative Fit Index; SRMR = Standardised Root Mean Square Residual

DISCUSSION

The present study aimed to further understand the relationships between change in illness perceptions and outcomes in psychosis and bipolar, including the direction of these relationships, during CBTp. The overarching purpose was to inform the inclusion of illness perceptions as therapeutic targets in intervention. Two specific hypotheses were tested.

Hypothesis 1: More positive or adaptive illness perceptions prior to starting therapy will predict better engagement

Two dimensions of illness perceptions predicted engagement in therapy. Those who engaged in therapy had significantly lower perceptions of personal control and higher perceptions that talking therapy would be helpful compared to those who did not engage. The other eight illness perceptions were similar across both those who engaged in therapy and those who did not, suggesting they were not associated with engagement.

The relationship between engagement and treatment control was in the expected direction and supports hypothesis 1. However, the relationship between engagement and perceptions of personal control was in the opposite direction and did not support the hypothesis. The other eight illness perceptions also did not support the hypothesis, showing no association in either direction.

The finding of pre-therapy perceptions that talking therapy would be helpful predicted better engagement is consistent with previous literature which assessed this relationship within a CBTp trial (Freeman et al., 2013) and within a cross-sectional study which assessed self-reported engagement (Shah et al., 2009).

These studies both found relationships between perceptions of timeline and engagement, whereby perceptions of a longer timeline were associated with better self-reported engagement (Shah et al., 2009) and with engagement in full or no therapy compared to partial therapy (Freeman et al., 2013). In the present study, mean scores indicated perceptions of a longer timeline for those who engaged in therapy, however the comparison with those who did not engage was not significant.

There was no indication of a non-linear relationship with personal or treatment control when engagement was categorised as receipt of full, partial or no therapy, which was not consistent with a previous study which assessed illness perceptions using a composite subscale of cure/control as part of a CBTp treatment trial (Freeman et al., 2013). There appeared to be potentially non-linear relationships for some dimensions, for instance, where there were perceptions of worse consequences and less coherence in the full and no therapy groups compared to the partial therapy group, however these differences were not statistically significant. Severity of symptoms appeared to be associated with engagement, whereby those who engaged in therapy had significantly higher severity of voice hearing pre-therapy compared to those who did engage. Severity of delusional beliefs was not associated with engagement in therapy. This is partly consistent with a previous study which found that severity of symptoms did not predict engagement (Freeman et al., 2013).

Overall, there is very limited previous literature investigating whether illness perceptions can predict engagement in psychological therapy. Although perceptions of personal control did not support the hypothesis, it makes logical sense that perceptions of high personal control were associated with lower engagement because if an individual feels they have control over their mental health problems and that it would be easy to improve them by their own efforts, then they may not perceive a need for therapy. However, if an individual perceives they do not have control over their mental health problems and would be unable to improve by their own effort then they may be more likely to seek support from others. It also makes sense that if individuals do not think that talking therapy can help with their mental health then they are less likely to engage in it. However, it was interesting that there was no difference for the items assessing CBT specific ideas between those who engaged and those who did not. This suggests that engagement in therapy may be predicted by more general perceptions of talking therapy, rather than by 'buy-in' to specific CBT principles. It would be interesting to further explore how talking therapy is perceived to be helpful in future research.

Hypothesis 2: Change to more positive or adaptive illness perceptions during CBTp will be associated with a reduction psychological distress during therapy

Overall, illness perceptions predicted change in levels of distress, for perceptions of symptom identity and that changing the way you think or do things can improve mental health. Thus, hypothesis 2 was only supported for these two illness perception dimensions. However, the effect sizes were larger for the cross

lagged path in the other direction, indicating a potentially reciprocal effect. Hypothesis 2 was not supported for the other eight illness perception dimensions. Levels of distress predicted change in illness perceptions across six dimensions, without a reciprocal effect. These dimensions included: consequences, personal control, concern, coherence, emotional response, and looking at things differently as helpful. No causal effects were found in either direction for two dimensions: perceptions of timeline or treatment control.

Levels of distress predicted illness perceptions without a reciprocal effect, across six dimensions. Pre-therapy levels of distress predicted change in perceptions of consequences, personal control, concern, coherence, emotional response, and looking at things differently as helpful in the first part of therapy. The effect sizes were smaller for change in levels of distress during the first part of therapy predicting change in perceptions of consequences, coherence, emotional response throughout therapy, and these paths did not reach significance. The effect size was similar for change in levels of distress during the first part of therapy predicting change in perceptions of concern throughout therapy. The effect size increased for change in levels of distress during the first part of therapy predicting change in perceptions of personal control throughout therapy. These effects were not present in the other direction: consequences, coherence, personal control, concern, emotional response, and looking at things differently did not predict change in levels of distress.

These findings may reflect biological processes involved in the flight or fight response which impact cognitive abilities (Steimer, 2002). If participants had high levels of distress at the beginning of therapy this may have affected their ability to view their mental health problems as understandable and consider that looking at things differently may be helpful. Therapy in the present study lead to reductions in distress, which may explain why these causal effects reduced for the majority of these dimensions later in therapy. These findings may also relate to the impact of mood on thinking biases, for instance, catastrophising, viewing things with a negative lens. CBTp has been shown to improve mood (NICE, 2014a, 2014b), thus perhaps when mood is lifted, individuals are able to feel more positive about their mental health problems. Additionally, levels of distress may reduce due to a number of reasons beyond changing appraisals or perceptions. Individuals may have found other ways to cope and manage, for example, behaviour strategies. This would be consistent with evidence from meta-analyses which found that behavioural components of CBT produced greater effect sizes (Wykes, Steel, Everitt, & Tarrier, 2008). This could also explain why the effect of levels of distress on perceived personal control increases during therapy, because if individuals have found ways to manage their mental health problems and experienced a reduction in distress, then it would make sense that they feel more in control of them and find it easier to improve them by their own efforts. Perhaps the experiential process of feeling less distressed is important as it provides individuals with evidence that they are able to exert some control over their mental health problems using their own efforts.

These interpretations would be in line with service user consultation on the findings where the experience of mental health problems prior to and at the beginning of therapy was described difficult to understand at the time because you are "so involved and it takes you over", you "lose yourself", and "you feel like a puppet". The importance of "taking back control" was emphasised, in addition to how it is 'down to the individual' to make changes. Around mid-therapy, the experience is that "you are just starting to have the option to understand" which includes that therapy cannot cure symptoms, but tools can be used to help cope with them.

Pre-therapy perceptions of symptom identity predicted change in levels of distress during the first part of therapy. Pre-therapy levels of distress also predicted change in perceptions of identity in the first part of therapy, with a larger effect size. These effects were smaller for change in symptom identity in the first part of therapy predicting change in levels of distress throughout therapy and vice versa, which did not reach significance. The reduced effect seen in perceptions of symptom identity predicting levels of distress later in therapy is in line with service user consultation, where a key process was explained in that during therapy it is learnt that anomalous experiences, for example, "hearing voices, cannot harm you" and therefore "you change your view of symptoms which reduces fear and distress". Additionally, it was explained that "using techniques to feel more present can help with carrying on with a task at hand despite the voice, which helps with taking more charge". The link between acute distress triggering voices could explain the causal effect in the other direction (Thomas et al., 2014).

Effects were present in both directions for perceptions of changing the way you think or do things can improve mental health with similar effect sizes. Change in these perceptions in the first part of therapy predicted change in levels of distress throughout therapy. Change in levels of distress in the first part of therapy predicted change in perceptions of changing the way you think or do things can improve mental health throughout therapy. These findings suggest that an increase in consideration that alternative ways of thinking or doing things might be helpful improves the likelihood of reducing distress during therapy, which is in line with CBT principles. This is supported by the finding that correlations between these items and levels of distress increase during therapy. Service user consultation suggested that these findings could reflect that pre-therapy, "individuals may not be aware that there is an alternative way to think or do things and that it can be hard to change beliefs". However, during the therapy process "you start to take on board what the therapist is saying, begin to reflect, consider options, and test things out". There is then "a lightbulb moment where you realise you have a choice of how to respond and you do not have to continue with previous ways of thinking or doing things". This perspective indicates how it may be more challenging to consider alternative ways of thinking or doing things earlier in therapy, and perhaps starting with small behaviour goals, experiencing some improvements in mood, and beginning to explore alternative primary appraisals may led onto opportunities for shifts in illness perceptions later on in therapy. These findings are in the context of the therapy process of usual treatment which did not explicitly target illness perceptions, therefore further research would be needed to test out these interpretations.

No causal effects were found for either perceptions of timeline or treatment control with levels of distress in either direction. It is interesting that perceptions of a longer timeline predicted better engagement in therapy but did not appear to relate to change in levels of distress. There may be some ambiguity in the timeline item whereby it is not obvious which direction would represent a more positive or adaptive illness perception (discussed further in study limitations). Additionally, it is surprising that treatment control did not relate to levels of distress, while causal effects were found with the items which assessed CBT ideas. This potentially demonstrates a key mechanism for how therapy reduces distress, which is the internalising of beliefs that an individual can do things or look at things differently to improve their mental health. Therefore, active participation and taking ownership of recovery appears to be more important than perceptions of talking therapy in general. This is consistent with previous research indicating that actively engaging the CBT techniques is required for therapy to be effective (Dunn et al., 2012).

Limitations

Measure of engagement

Engagement was operationalised as number of sessions attended and categorised according to cut-offs used in previous studies assessing CBTp in similar services (Johns et al., 2019). This is only a proxy measure of engagement as it does not capture any information about active engagement in CBT techniques and strategies. Service user consultation indicated that individuals could attend therapy sessions but not actively engage in the content of the session. Additionally, it was highlighted that lower attendance may instead reflect broader issues, for example, memory difficulties or if service users are not able to travel on their own then cancellations may occur for reasons related those accompanying them. Furthermore, a culture of secrecy around accessing help around mental health may impact on service users' attendance for sessions.

Measure of illness perceptions

There was some ambiguity in the language of items used to assess illness perceptions, and it was not clear how individuals interpret "mental health problem". This could be considered to be psychosis symptoms, however if they do not agree with their diagnosis then they may consider this to refer to anxiety or affective symptoms.

There is an issue with considering illness perceptions as positive or negative, as it is not obvious or well understood what direction would be considered more "positive". "Adaptive" was used to somewhat overcome this issue, however evidence suggests that this may vary depending on what outcome is being considered. For example, perceptions of a longer timeline may be considered less adaptive or more negative but has been associated with better engagement in therapy (Freeman et al., 2013), on the understanding that something lasting a long time should be taken seriously and requires intervention.

However, longer timeline correlated with higher levels of distress in the present study at each time point and with a range of poorer outcomes in cross-sectional correlations in previous studies, including: higher levels of anxiety and depression (Cavelti, Beck, Kvrgic, Kossowsky, & Vauth, 2012a; Cavelti et al., 2012b; Lobban et al., 2004; Lobban, Barrowclough, & Jones, 2005; Watson et al., 2006), lower wellbeing (Cavelti et al., 2012b), poorer quality of life (Lobban et al., 2004), more severe symptoms (Fialko et al., 2006; Lobban et al., 2005), and suicidal ideation (Fialko et al., 2006). Therefore, further research should be wary of using total scores of illness perception.

Issues of Circularity

There are potential issues of circularity between variables in this study, whereby some dimensions of illness perceptions may simply reflect changes in levels of distress rather than predict them. This is more likely with the dimensions which are more closely related to levels of distress, for example, perceptions of emotional impact, concern, and consequences. The present study attempted to overcome this issue by using cross lagged panel analyses which enabled the relationships to be assessed in both directions. The findings indicated considerably larger effect sizes in the direction of levels of distress predicting perceptions of emotional impact, concern, and consequences compared to the opposite direction. This suggests that the findings of this study do not simply reflect circularity between variables.

Illness perception models

The present study did not assess the coping styles or behaviours part of the SRM model, therefore it is not known whether to what degree they play a role in the mechanisms through which illness perceptions and levels of distress interact during therapy. The present study did not assess illness perceptions based on social rank theory, for instance, perceptions of shame and humiliation assessed by the PBIQ (Birchwood et al., 1993). Illness perceptions and levels of distress interact within a social context, which may impact on the relationship between them. Additionally, the formation of illness perceptions is likely to have been influenced by an individual's social and cultural context. Further research is needed to understand how the social and cultural context of illness perceptions impact on outcomes in psychosis and bipolar.

Study design

This study utilised a cohort CBTp design with data from a clinical service. There was no control group and illness perceptions were not targeted for change during CBTp. Therefore, change in illness perceptions observed in the present study was as part of normal clinical care within the service with no manipulation of an independent variable. This somewhat limits causal inferences that can be made from findings and the quality of evidence that the present study provides for the effect of change in illness perceptions on change in level of distress. Hypothesis 2 was investigated with a subsample of participants who did engage

in therapy, therefore findings do not represent the causal relationships between illness perceptions and levels of distress for those who dropped out of therapy.

Multiple comparisons

Ten dimensions of illness perception were assessed in the present study. Analyses were carried out separately for each dimension. Adjustments for multiple comparisons (e.g. Bonferroni correction) were not applied for hypothesis 1 analyses in attempt to balance between the likelihood of type 1 and type 2 error. The effect sizes of baseline illness perceptions which significantly predicted engagement in therapy were small. This hypothesis aimed to uncover potential predictors of engagement in therapy, which could indicate areas of further research, therefore it was important to not apply conservative adjustments for multiple comparisons which would increase the change of type 2 error. Furthermore, the risk of type 1 errors in the context of exploring predictors of engagement would not be as detrimental compared to studies investigating the effectiveness of treatments. Additionally, as the analyses were carried out separately for each dimension, the findings do not indicate whether certain combinations of illness perceptions dimensions relate more closely to engagement in therapy or distress outcomes. It would be worthwhile for future research to investigate this.

Strengths of present study

The present study was the first to the author's knowledge to examine the relationship between change in illness perceptions and distress outcomes. The statistical method used allowed for change in both illness perceptions and levels of distress during therapy to be examined over time and to assess causal relationships in both directions. The present study used a modified version of the BIPQ which included two additional items (taken from a modified version of the IPQ; Marcus et al., 2014) which assessed illness perceptions in relation to a specific treatment, namely CBT. Including perceptions of specific treatments was recommended by a previous narrative review (Lobban et al., 2003). This enabled outcomes of CBTp to be assessed in relation to specific perceptions of CBT as a treatment and thus increasing the relevance. The different findings in the present study for items assessing perceptions of illness as treatable by treatment in general compared to those for specific CBT related perceptions suggest that future research should consider assessing perceptions of treatment control in relation to specific treatment. Another strength of the present study is the diversity in relation to ethnicity and age across working aged adults within the sample, which increases the generalisability of the findings.

Clinical Implications

The purpose of the present study was to elucidate the potential benefit of targeting illness perceptions as a component of therapeutic change. The complexity of the findings, while not refuting this possibility, do not allow straightforward conclusions to be drawn regarding clinical practice. Rather, findings highlight the

potential for reciprocal relationships between change in levels of distress and illness perceptions (and potentially other secondary appraisals). Subject to confirmation in further research, such reciprocity could inform therapy developments. For example, if improving mood leads to more positive illness perceptions, targeting mood early in therapy (as is often recommended) could support change in secondary appraisals. Targeting the secondary appraisal changes that influence distress, particularly the belief that changing thoughts or behaviour may be helpful, may also improve mood, and thus have further effects on other illness perceptions. Again, it would be recommended, in socialising a person to CBTp, that this idea would be introduced early in therapy. Nevertheless, attention to individualised appraisals, affective responses, and patterns of change should dictate the content of early sessions. The findings fit with the consultation with service users as part of the present study, which was incredibly valuable to gain a more in depth understanding of therapy change processes and the role of illness perceptions. Service user perspective studies similarly highlight the importance of embracing cognitive and behavioural change processes (Wood, Burke, & Morrison, 2015). Service user perspectives should be explored in future research to further understand the interrelationships of change and to resolve the ambiguity around some dimensions of illness perceptions, where it is not clearly understood which direction is more adaptive for coping and better outcomes. For example, the association between perceptions of a longer timeline and better engagement in therapy. Further understanding of the 'ingredients of the therapy process' and how change in facilitated is required; consulting with service users who have dropped out or not had a good response from therapy would be beneficial (Wood, Burke, & Morrison, 2015). Although research is crucial for providing evidence about the effectiveness of treatment, it is important to recognise the importance of using individual formulations of change processes. The inclusion of secondary appraisals and interrelationships of these, as part of individual formulations could provide additional understanding of difficulties and needs to inform personalised therapeutic interventions.

Future research

Future research could utilise a CBTp intervention to target specific illness perceptions earlier on in therapy to ascertain whether this change can improve outcomes. It would be worth assessing coping styles and behaviours during CBTp, in line with the SRM, to investigate the mechanisms through which change in illness perceptions could impact therapy outcomes. Additionally, broadening the dimensions of illness perceptions to include those which relate to social context and social rank theory could provide new understanding. Dimensions of illness perceptions were analysed separately in the present study, therefore this does not provide information about whether combinations of perceptions are important for predicting outcomes. It has been suggested that certain patterns of illness perceptions may be help to predict outcomes better than single dimensions (Lobban et al., 2003). Future research could consider whether there are key illness perceptions, which in combination can predict engagement and outcomes of therapy, for example, perceptions of low personal control together with perceptions that talking therapy would be

helpful. Future studies should examine the relationship in both directions as there is a dearth of studies investigating the causal role of level of distress on illness perceptions despite findings the present study suggesting that causal effects may be stronger in this direction. Based on variation in findings between illness perceptions dimensions, it is not recommended to use total score as this makes assumptions about in what direction an illness perception is adaptive and potentially dilutes effects. Additionally, it is recommended to assess active engagement in therapy, rather than using a proxy based on number of sessions.

Conclusion

The present study aimed to further understand the relationships between change in dimensions of illness perceptions and outcomes in psychosis and bipolar, including the direction of these relationships. These relationships were studied within the context of CBTp as some dimensions of illness perceptions have previously shown they were changeable during therapy. Findings indicated that those who engaged in therapy had significantly lower perceptions of personal control and higher perceptions that talking therapy would be helpful compared to those who did not engage. During therapy, illness perceptions predicted change in levels of distress, for perceptions of symptom identity and that changing the way you think or do things can improve mental health. Levels of distress predicted change in illness perceptions across six dimensions including: consequences, personal control, identity, concern, coherence, emotional response, changing the way you think or do things can improve mental health, and looking at things differently as helpful. No causal effects were found for either perceptions of timeline or treatment control with levels of distress in either direction. These findings suggest a strong causal role for distress on illness perceptions which has been neglected in previous research. Findings are potentially supportive of the possibility of incorporating explicit illness perception interventions into CBTp, but highlight the need for further controlled, longitudinal studies.

References

Amador, X. F., Strauss, D. H., Yale, S. A., Flaum, M. M., Endicott, J., & Gorman, J. M. (1993). Assessment of insight in psychosis. *American journal of Psychiatry, 150*, 873-873.

Barkham, M., Bewick, B., Mullin, T., Gilbody, S., Connell, J., Cahill, J., . . . Evans, C. (2013). The CORE-10: A short measure of psychological distress for routine use in the psychological therapies. Counselling and Psychotherapy Research, 13(1), 3-13.

Bentler, P. M., & Bonett, D. G. (1980). Significance tests and goodness of fit in the analysis of covariance structures. Psychological bulletin, 88(3), 588.

Berk, M., Berk, L., Dodd, S., Fitzgerald, P. B., de Castella, A. R., Filia, S., . . . Montgomery, W. (2013). The sick role, illness cognitions and outcomes in bipolar disorder. Journal of affective disorders, 146(1), 146-149.

Birchwood, M., Iqbal, Z., & Upthegrove, R. (2005). Psychological pathways to depression in schizophrenia. European archives of psychiatry and clinical neuroscience, 255(3), 202-212.
Birchwood, M., Mason, R., MacMillan, F., & Healy, J. (1993). Depression, demoralization and control over psychotic illness: a comparison of depressed and non-depressed patients with a chronic psychosis. Psychological medicine, 23(2), 387-395.
Broadbent, E., Petrie, K., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. Journal of psychosomatic research, 60(6), 631-637.
Broadbent, E., Wilkes, C., Koschwanez, H., Weinman, J., Norton, S., & Petrie, K. J. (2015). A systematic review and meta-analysis of the Brief Illness Perception Questionnaire. Psychol Health, 30(11), 1361-1385. doi:10.1080/08870446.2015.1070851
Cavelti, M., Beck, E. M., Kvrgic, S., Kossowsky, J., & Vauth, R. (2012a). The role of subjective illness beliefs and attitude toward recovery within the relationship of insight and depressive symptoms among people with schizophrenia spectrum disorders. Journal of clinical psychology, 68(4), 462-476.
Cavelti, M., Contin, G., Beck, E.-M., Kvrgic, S., Kossowsky, J., Stieglitz, R.-D., & Vauth, R. (2012b). Validation of the Illness Perception Questionnaire for Schizophrenia in a German-speaking sample of outpatients with chronic schizophrenia. Psychopathology, 45(4), 259-269.
Chadwick, P., Williams, C., & Mackenzie, J. (2003). Impact of case formulation in cognitive behaviour therapy for psychosis. Behaviour research and therapy, 41(6), 671-680.
Charles, C., Ninot, G., & Sultan, S. (2011). Patients' illness perceptions and adherence to treatment with inhaled corticosteroids in asthma. Revue des maladies respiratoires, 28(5), 626-635.
Clarke, A. L., Yates, T., Smith, A. C., & Chilcot, J. (2016). Patient's perceptions of chronic kidney disease and their association with psychosocial and clinical outcomes: a narrative review. Clin Kidney J, 9(3), 494-502. doi:10.1093/ckj/sfw014
Cohen, J. (2013). Statistical power analysis for the behavioral sciences: Academic press.
Dee, D. P., & Da Silva, A. M. (1999). Maximum-likelihood estimation of forecast and observation error covariance parameters. Part I: Methodology. Monthly Weather Review, 127(8), 1822-1834.
Drake, R., Haddock, G., Tarrier, N., Bentall, R., & Lewis, S. (2007). The Psychotic Symptom Rating Scales (PSYRATS): their usefulness and properties in first episode psychosis. Schizophrenia research, 89(1-3), 119-122.
Drury, V., Birchwood, M., & Cochrane, R. (2000). Cognitive therapy and recovery from acute psychosis: A controlled trial: 3. Five-year follow-up. The British Journal of Psychiatry, 177(1), 8-14.
Dunn, G., Fowler, D., Rollinson, R., Freeman, D., Kuipers, E., Smith, B., . . . Garety, P. (2012). Effective elements of cognitive behaviour therapy for psychosis: results of a novel type of subgroup analysis based on principal stratification. Psychological medicine, 42(5), 1057-1068.
Eekhout, I., de Vet, H. C. W., Twisk, J. W. R., Brand, J. P. L., de Boer, M. R., & Heymans, M. W. (2014). Missing data in a multi-item instrument were best handled by multiple imputation at the item score level. Journal of clinical epidemiology, 67(3), 335-342.
Etain, B., Scott, J., Cochet, B., Bellivier, F., Boudebesse, C., Drancourt, N., . . . Fouques, D. (2018). A study of the real-world effectiveness of group psychoeducation for bipolar disorders: Is change in illness perception a key mediator of benefit? Journal of affective disorders, 227, 713-720.
Fialko, L., Freeman, D., Bebbington, P. E., Kuipers, E., Garety, P. A., Dunn, G., & Fowler, D. (2006). Understanding suicidal ideation in psychosis: findings from the Psychological Prevention of Relapse in Psychosis (PRP) trial. Acta Psychiatrica Scandinavica, 114(3), 177-186.
Freeman, D., Dunn, G., Garety, P., Weinman, J., Kuipers, E., Fowler, D., . . . Bebbington, P. (2013). Patients' beliefs about the causes, persistence and control of psychotic experiences predict take-

up of effective cognitive behaviour therapy for psychosis. Psychological medicine, 43(2), 269-277.

Garety, P. A., Fowler, D. G., Freeman, D., Bebbington, P., Dunn, G., & Kuipers, E. (2008). Cognitive-behavioural therapy and family intervention for relapse prevention and symptom reduction in psychosis: randomised controlled trial. The British Journal of Psychiatry, 192(6), 412-423.

Grant, N. (2016). Doctoral Thesis. (Doctor of Clinical Psychology). King's College London,

Gumley, A., Karatzias, A., Power, K., Reilly, J., McNay, L., & O'Grady, M. (2006). Early intervention for relapse in schizophrenia: Impact of cognitive behavioural therapy on negative beliefs about psychosis and self-esteem. British Journal of Clinical Psychology, 45(2), 247-260.

Haddock, G., McCarron, J., Tarrier, N., & Faragher, E. B. (1999). Scales to measure dimensions of hallucinations and delusions: the psychotic symptom rating scales (PSYRATS). Psychol Med, 29(4), 879-889. doi:10.1017/s0033291799008661

Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. Psychology and health, 18(2), 141-184.

Hasler, G., Klaghofer, R., & Buddeberg, C. (2003). The university of rhode island change assessment scale (URICA). Psychotherapie, Psychosomatik, Medizinische Psychologie, 53(9-10), 406-411.

Hu, L. t., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. Structural equation modeling: a multidisciplinary journal, 6(1), 1-55.

Iqbal, Z., Birchwood, M., Chadwick, P., & Trower, P. (2000). Cognitive approach to depression and suicidal thinking in psychosis: 2. Testing the validity of a social ranking model. The British Journal of Psychiatry, 177(6), 522-528.

Johns, L., Jolley, S., Garety, P., Khondoker, M., Fornells-Ambrojo, M., Onwumere, J., . . . Byrne, M. (2019). Improving Access to psychological therapies for people with severe mental illness (IAPT-SMI): Lessons from the South London and Maudsley psychosis demonstration site. Behaviour research and therapy, 116, 104-110.

Leventhal, H., Nerenz, D., & Steele, D. (1984). Illness representations and coping with health threats. In A. B. J. Singer (Ed.), A handbook of psychology and health (pp. 219 – 252). Hillsdale, NJ: Erlbaum.

Lobban, F., Barrowclough, C., & Jones, S. (2003). A review of the role of illness models in severe mental illness. Clinical psychology review, 23(2), 171-196.

Lobban, F., Barrowclough, C., & Jones, S. (2004). The impact of beliefs about mental health problems and coping on outcome in schizophrenia. Psychological medicine, 34(7), 1165-1176.

Lobban, F., Barrowclough, C., & Jones, S. (2005). Assessing cognitive representations of mental health problems. I. The illness perception questionnaire for schizophrenia. British Journal of Clinical Psychology, 44(2), 147-162.

Lobban, F., Solis-Trapala, I., Tyler, E., Chandler, C., Morriss, R. K., & Group, E. R. P. (2013). The role of beliefs about mood swings in determining outcome in bipolar disorder. Cognitive therapy and research, 37(1), 51-60.

Maguire, P. A., Reay, R. E., & Raphael, B. (2016). Correlates of a single-item Self-Rated Mental Health Question in people with schizophrenia. Australasian Psychiatry, 24(5), 473-477.

Marcus, E., Garety, P., Weinman, J., Emsley, R., Dunn, G., Bebbington, P., . . . Hardy, A. (2014). A pilot validation of a modified Illness Perceptions Questionnaire designed to predict response to cognitive therapy for psychosis. Journal of behavior therapy and experimental psychiatry, 45(4), 459-466.

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). Psychology and health, 17(1), 1-16.

Murphy, J., McSharry, J., Hynes, L., Matthews, S., Van Rhoon, L., & Molloy, G. J. (2020). Prevalence and predictors of adherence to inhaled corticosteroids in young adults (15-30 years) with asthma: a systematic review and meta-analysis. J Asthma, 1-23. doi:10.1080/02770903.2020.1711916

Newsom, J. T. (2015). Longitudinal structural equation modeling: A comprehensive introduction: Routledge.

NICE. (2014a). Psychosis and schizophrenia in adults: Prevention and management. Retrieved from https://www.nice.org.uk/guidance/cg178

NICE. (2014b). Bipolar disorder: assessment and management. Retrieved from https://www.nice.org.uk/guidance/cg185

Proudfoot, J., Parker, G., Manicavasagar, V., Hadzi-Pavlovic, D., Whitton, A., Nicholas, J., . . . Burckhardt, R. (2012). Effects of adjunctive peer support on perceptions of illness control and understanding in an online psychoeducation program for bipolar disorder: a randomised controlled trial. Journal of affective disorders, 142(1-3), 98-105.

Prytys, M., Garety, P. A., Jolley, S., Onwumere, J., & Craig, T. (2011). Implementing the NICE guideline for schizophrenia recommendations for psychological therapies: a qualitative analysis of the attitudes of CMHT staff. Clinical psychology & psychotherapy, 18(1), 48-59.

Rooke, O., & Birchwood, M. (1998). Loss, humiliation and entrapment as appraisals of schizophrenic illness: A prospective study of depressed and non-depressed patients. British Journal of Clinical Psychology, 37(3), 259-268.

Ross, S., Walker, A., & MacLeod, M. J. (2004). Patient compliance in hypertension: role of illness perceptions and treatment beliefs. J Hum Hypertens, 18(9), 607-613. doi:10.1038/sj.jhh.1001721

Rosseel, Y. (2012). Lavaan: An R package for structural equation modeling and more. Version 0.5–12 (BETA). Journal of statistical software, 48(2), 1-36.

Shah, P., Hull, T., & Riley, G. A. (2009). Associations between the Illness Perception Questionnaire for Schizophrenia and engagement in treatment in a secure setting. Clinical Psychologist, 13(2), 69-74.

Stainsby, M., Sapochnik, M., Bledin, K., & Mason, O. J. (2010). Are attitudes and beliefs about symptoms more important than symptom severity in recovery from psychosis? Psychosis, 2(1), 41-49.

Steimer, T. (2002). The biology of fear-and anxiety-related behaviors. Dialogues in clinical neuroscience, 4(3), 231.

Team, R. C. (2017). R: A language and environment for statistical computing. R Foundation for Statistical Computing. Retrieved from Vienna, Austria: https://www.R-project.org/.

Thomas, N., Hayward, M., Peters, E., Van Der Gaag, M., Bentall, R. P., Jenner, J., . . . Varese, F. (2014). Psychological therapies for auditory hallucinations (voices): current status and key directions for future research. Schizophrenia Bulletin, 40(Suppl_4), S202-S212.

Wanous, J. P., Reichers, A. E., & Hudy, M. J. (1997). Overall job satisfaction: how good are single-item measures? Journal of applied Psychology, 82(2), 247.

Watson, P. W. B., Garety, P. A., Weinman, J., Dunn, G., Bebbington, P. E., Fowler, D., . . . Kuipers, E. (2006). Emotional dysfunction in schizophrenia spectrum psychosis: the role of illness perceptions. Psychological medicine, 36(6), 761-770.

Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: a new method for assessing the cognitive representation of illness. Psychology and health, 11(3), 431-445.

Wood, L., Burke, E., & Morrison, A. (2015). Individual cognitive behavioural therapy for psychosis (CBTp): a systematic review of qualitative literature. Behavioural and Cognitive Psychotherapy, 43(3), 285-297.

Woodward, T. S., Jung, K., Hwang, H., Yin, J., Taylor, L., Menon, M., . . . Erickson, D. (2014). Symptom Dimensions of the Psychotic Symptom Rating Scales in Psychosis: A Multisite Study. Schizophrenia Bulletin, 40(Suppl_4), S265-S274. doi:10.1093/schbul/sbu014

Wykes, T., Steel, C., Everitt, B., & Tarrier, N. (2008). Cognitive behavior therapy for schizophrenia: effect sizes, clinical models, and methodological rigor. Schizophrenia Bulletin, 34(3), 523-537.

Appendix A: Summary notes of consultation with Peer Recovery Lead at PICuP

The Peer Recovery Lead at PICuP was consulted to gain their perspective, insights and advice. They were approached for consultation as they were already familiar with the service, its functions and were well supported in their role. Their perspective was based on their own experience of CBTp at PICuP and also the perspectives of other service users they had supported and had conversations with as part of their role. Two meetings were scheduled with the following aims:

3. To discuss the design of the study and measurement of what we are investigating, e.g. how to capture/measure "engagement" with CBTp.
4. To discuss the interpretation of findings including anything unexpected and to discuss/plan writing up and dissemination.

The discussions during the meetings are summarised below.

Engagement

Therapists are understood to deliver therapy based on their own individual style. The factors perceived as important to facilitate good engagement included building the relationship with the therapist through viewing them as approachable, as someone they could trust, as holding the service users' best interests in mind, and as "human" with flaws themselves. Barriers to engagement could include the service user not wanting to burden the therapist and therefore holding back on disclosing information.

The challenges of capturing and measuring engagement within the scope of this project were discussed. The potential proxy measurement of engagement using number of therapy sessions attended has limitations. Service users could attend therapy sessions but not engage in the content of the session. Lower attendance may instead reflect broader issues, for example, memory difficulties or if service users are not able to travel on their own, cancellations may occur for reasons related those accompanying them. Additionally, a culture of secrecy around accessing help around mental health may impact on service users' attendance for sessions.

Mechanisms of change in therapy

Before starting therapy, symptoms experienced by service users can often be associated with feelings of being "taken over" and "losing control over me". It was reported that these feelings may be more distressing compared to the content of anomalous experiences. Therefore, a key component of therapy important for its effectiveness included "taking back control" and how it is down to the individual to make changes - it was estimated that changes in illness perceptions occur around the middle of therapy or just after. Therapy was also helpful in meeting the need to learn to love yourself and increase self-compassion. A key change in perception that occurred during therapy for this service user was a shift from viewing their anomalous experiences as terrifying to viewing them with curiosity and owning the lived experience. This resulted in a shift of feeling terrified by them, to fascinated.

Other components that were perceived to be integral to recovery included: containment from the structure of sessions, homework tasks between sessions including using a diary, reading materials and practical task to help increase awareness, knowledge, and maximise learning between sessions. Other aspects of therapy that were appreciated include the holistic approach of therapy, for example, addressing sleep, and being person centred, for instance, the therapist asking what the service user would like to talk about which allowed the therapy to be tailored to individual needs. Spaced out sessions towards the end of therapy can be helpful to test out how to manage without therapy. Therapy can be seen as a safety net and it can be common to feel high about finishing but also be worried about relapse.

Appendix B – Modified BIPQ

Brief IPQ (PICuP modified version; August 2012)

Here are some general questions about your mental health problems.
For each question, please circle the number that best corresponds to your views (please note there are no right or wrong answers):

1. How much do your mental health problems affect your life?

0 1 2 3 4 5 6 7 8 9 10
no affect at all — severely affects my life

2. How long do you think your mental health problems will continue?

0 1 2 3 4 5 6 7 8 9 10
a very short time — forever

3. How much control do you feel you have over your mental health problems (that is, how easy would it be for them to improve by your own efforts)?

0 1 2 3 4 5 6 7 8 9 10
absolutely no control — total control

4. How much do you experience 'symptoms' from your mental health problems?

0 1 2 3 4 5 6 7 8 9 10
no symptoms at all — many severe symptoms

5. How concerned are you about your mental health problems?

0 1 2 3 4 5 6 7 8 9 10
not at all concerned — extremely concerned

6. How well do you feel you understand your mental health problems?

0 1 2 3 4 5 6 7 8 9 10
don't understand at all — understand very clearly

7. How much do your mental health problems *affect you* emotionally? (eg. does it make you angry, scared, upset or depressed?)

0 1 2 3 4 5 6 7 8 9 10
not at all emotionally affected — extremely emotionally affected

8. How much do you think talking therapy can help with your mental health problems?

0 1 2 3 4 5 6 7 8 9 10
not at all — extremely helpful

9. How much do you think changing the way you think or the way you do things can improve your mental health problems?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely

10. How much do you think looking at things differently can be helpful?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely

CAUSES OF MY MENTAL HEALTH PROBLEMS

We are interested in what you consider may have been the causes of your mental health problems. As people are very different, there is no correct answer for this question. We are most interested in your own views rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your mental health problems. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	Possible Causes	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
C1	Stress or worry					
C2	Hereditary; it runs in my family					
C3	My mental attitude e.g.; thinking about life negatively					
C4	Family problems					
C5	Taking illicit drugs					
C6	My personality					
C7	No close friend					
C8	Chemical imbalance in the brain					
C9	A trauma; something disturbing or shocking that happened in my life					
C10	Lack of sleep					
C11	My upbringing					
C12	Being bullied at school or college					
C13	Other: (please specify)					

Thank you

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adapted from B-IPQ (Broadbent et al 06)

CLINICAL OUTCOMES IN ROUTINE EVALUATION

CORE 10

IMPORTANT – PLEASE READ THIS FIRST

This form has 10 statements about how you have been OVER THE LAST WEEK.
Please read each statement and think how often you felt that way last week.
Then tick the box which is closest to this.

Please use a dark pen (not pencil) and tick clearly within the boxes.

Over the last week	*Not at all*	*Only occasionally*	*Sometimes*	*Often*	*Most or all of the time*
1. I have felt tense, anxious or nervous	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
2. I have felt I have someone to turn to for support when needed	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
3. I have felt able to cope when things go wrong	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
4. Talking to people has felt too much for me	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
5. I have felt panic or terror	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
6. I made plans to end my life	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
7. I have had difficulty getting to sleep or staying asleep	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
8. I have felt despairing or hopeless	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
9. I have felt unhappy	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4
10. Unwanted images or memories have been distressing me	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4

Total ☐

Thank you for your time in completing this questionnaire

PSYRATS

A Voices

1 Frequency
0 Voices not present or present less than once a week
1 Voices occur for at least once a week
2 Voices occur at least once a day
3 Voices occur at least once a hour
4 Voices occur continuously or almost continuously i.e. stop for only a few seconds or minutes

2 Duration
0 Voices not present
1 Voices last for a few seconds, fleeting voices
2 Voices last for several minutes
3 Voices last for at least one hour
4 Voices last for hours at a time

3 Location
0 No voices present
1 Voices sound like they are inside head only
2 Voices outside the head, but close to ears or head. Voices inside the head may also be present
3 Voices sound like they are inside or close to ears and outside head away from ears
4 Voices sound like they are from outside the head only

4 Loudness
0 Voices not present
1 Quieter than own voice, whispers.
2 About same loudness as own voice
3 Louder than own voice
4 Extremely loud, shouting

5 Beliefs re-origin of voices
0 Voices not present
1 Believes voices to be solely internally generated and related to self
2 Holds < 50% conviction that voices originate from external causes
3 Holds ~ 50% conviction (but < 100%) that voices originate from external causes
4 Believes voices are solely due to external causes (100% conviction)

6 Amount of negative content of voices
0 No unpleasant content
1 Occasional unpleasant content (< 10%)
2 Minority of voice content is unpleasant or negative (< 50%)
3 Majority of voice content is unpleasant or negative (> 50%)
4 All of voice content is unpleasant or negative

7 Degree of negative content
0 Not unpleasant or negative
1 Some degree of negative content, but not personal comments relating to self or family e.g. swear words or comments not directed to self, e.g. 'the milkman's ugly'
2 Personal verbal abuse, comments on behavior e.g. ' shouldn't do that or say that ,
3 Personal verbal abuse relating to self-concept e.g. 'you're lazy, ugly, mad, perverted ,
4 Personal threats to self e.g. threats to harm self or family, extreme instructions or commands to harm self or others

8 Amount of distress
0 Voices not distressing at all
1 Voices occasionally distressing, majority not distressing (< 10%)
2 Minority of voices distressing (< 50%)
3 Majority of voices distressing, minority not distressing (~ 50%)
4 Voices always distressing

9 Intensity of distress
0 Voices not distressing at all
1 Voices slightly distressing
2 Voices are distressing to a moderate degree
3 Voices are very distressing, although subject could feel worse
4 Voices are extremely distressing, feel the worst he/she could possibly feel

10 Disruption to life caused by voices
0 No disruption to life, able to maintain social and family relationships (if present)
1 Voices causes minimal amount of disruption to life e.g. interferes with concentration although able to maintain daytime activity and social and family relationships and be able to maintain independent living without support
2 Voices cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The patient is not in hospital although may live in supported accommodation or receive additional help with daily living skills
3 Voices cause severe disruption to life so that hospitalisation is usually necessary . The patient is able to maintain some daily activities, self-care and relationships while in hospital. The patient may also be in supported accommodation but experiencing severe disruption of life in terms of activities, daily living skills and/or relationships
4 Voices cause complete disruption of daily life requiring hospitalization. The patient is unable to maintain any daily activities and social relationships. Self-care is also severely disrupted.

11 Controllability of voices
0 Subject believes they can have control over the voices and can always bring on or dismiss them at will
1 Subject believes they can have some control over the voices on the majority of occasions
2 Subject believes they can have some control over their voices approximately half of the time
3 Subject believes they can have some control over their voices but only occasionally. The majority of the time the subject experiences voices which are uncontrollable
4 Subject has no control over when the voices occur and cannot dismiss or bring them on at all

B Beliefs

1 Amount of preoccupation

0 None, or thinks about less than once a week
1 Subject thinks about beliefs at least once a week
2 Subject thinks about beliefs at least once a day
3 Subject thinks about beliefs at least once an hour
4 Subject thinks about delusions continuously or almost continuously

2 Duration of preoccupation

0 None
1 Thoughts about beliefs last for a few seconds, fleeting thoughts
2 Thoughts about delusions last for several minutes
3 Thoughts about delusions last for at least 1 hour
4 Thoughts about delusions usually last for hours at a time

3 Conviction

0 No conviction at all
1 Very little conviction in reality of beliefs, < 10%
2 Some doubts relating to conviction in beliefs, between 10-49%
3 Conviction in belief is very strong, between 50-99 %
4 Conviction is 100 %

4 Amount of distress

0 Beliefs never cause distress
1 Beliefs cause distress on the minority of occasions
2 Beliefs cause distress on < 50% of occasions
3 Beliefs cause distress on the majority of occasions when they occur between 50-99% of time
4 Beliefs always cause distress when they occur

5 Intensity of distress

0 No distress
1 Beliefs cause slight distress
2 Beliefs cause moderate distress
3 Beliefs cause marked distress
4 Beliefs cause extreme distress, could not be worse

6 Disruption to life caused by beliefs

0 No disruption to life, able to maintain independent living with no problems in daily living skills. Able to maintain social and family relationships (if present)
1 Beliefs cause minimal amount of disruption to life, e.g. interferes with concentration although able to maintain daytime activity and social and family relationships and be able to maintain independent living without support
2 Beliefs cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The patient is not in hospital although may live in supported accommodation or receive additional help with daily living skills
3 Beliefs cause severe disruption to life so that hospitalisation is usually necessary. The patient is able to maintain some daily activities, self-care and relationships while in hospital. The patient may be also be in supported accommodation but experiencing severe disruption of life in terms of activities, daily living skills and/or relationships
4 Beliefs cause complete disruption of daily life requiring hospitalization. The patient is unable to maintain any daily activities and social relationships. Self-care is also severely disrupted

NHS
Health Research Authority
London – Dulwich Research Ethics Committee
HRA
Skipton House
80 London Road
London SE1 6LH

Tel: 020 7104 8113
Email: nrescommittee.london-dulwich@nhs.net

15 January 2016

Dr Vaughan Bell
Psychological Interventions Clinic for outpatients with Psychosis (PICuP)
PO79, Maudsley Psychology Centre
Maudsley Hospital
Denmark Hill
London SE5 8AZ

Dear Dr Bell

Title of the Research Database:	**PICUP Research Database 1.0**
REC reference:	**15/LO/1831**
IRAS project ID:	**186407**

Thank you for your letter of 11 January 2016, responding to the Committee's request for further information on the above research database and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC manager, Mr Michael Higgs, nrescommittee.london-dulwich@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion of the above research database on the basis described in the application form and supporting documentation as revised.

Duration of ethical opinion

The favourable opinion is given for a period of five years from the date of this letter and provided that you comply with the standard conditions of ethical approval for Research Databases set out in the attached

The attached standard conditions give detailed guidance on reporting requirements for research databases with a favourable opinion, including:

- Notifying substantial amendments
- Submitting Annual Progress reports

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/LO/1831	**Please quote this number on all correspondence**

Yours sincerely

Dr Michael Philpot
Chair

E-mail: nrescommittee.london-dulwich@nhs.net

Enclosures: *Approval conditions*

Copy to: *Mr Ben Tunmore, Psychological Interventions Clinic for outpatients with Psychosis (PICuP)*

CONDITIONS OF ETHICAL APPROVAL

Research Ethics Committee:	London - Dulwich Research Ethics Committee
Research Database:	PICUP Research Database 1.0
Data Controller:	Mr Ben Tunmore
Establishment:	Psychological Interventions Clinic for outpatients with Psychosis (PICuP)
REC reference number:	15/LO/1831
Name of applicant:	Dr Vaughan Bell
Date of approval:	15 January 2016
IRAS project ID:	186407

Ethical approval is given to the Research Database team ("Database team") based within the Establishment by the Research Ethics Committee ("the Committee") subject to the following conditions.

1. Further communications with the Committee

1.1 Further communications with the Committee are the personal responsibility of the applicant.

2. Duration of approval

2.1 Approval is given for a period of 5 years, which may be renewed on consideration of a new application by the Committee, taking account of developments in legislation, policy and guidance in the interim. New applications should include relevant changes of policy or practice made by the establishment since the original approval together with any proposed new developments.

3. Generic approval for the Research Database team

3.1 Ethical approval is given for processing of personal data by the Research Database team for the purposes described in the application. This includes specific research projects undertaken by the Database team using the data, subject to the following

conditions:

3.1.1 The research project is within the fields of health or social care research described in the application.

3.1.2 The research protocol has been subject to scientific critique, is appropriately designed in relation to its objectives and (with the exception of student research below doctoral level) is likely to add something useful to existing knowledge.

3.1.3 The processing of the data will comply with the terms of informed consent from data subjects.

3.2 Any research project requiring researchers to undertake additional procedures involving subjects, other than data collection arrangements described in the application, is not covered by generic approval for the Database. Additional research procedures should be the subject of further ethical review, either as a substantial amendment to the terms of generic approval for the Database, or separate application for ethical review of a specific project.

3.3 A Notice of Substantial Amendment should be submitted to seek the Committee's agreement to change the conditions of generic approval for the Database.

4. Generic approval for external researchers

4.1 Data may be supplied and used in research projects to be conducted by researchers and research institutions outside of the Research Database team within the UK in accordance with the following conditions.

4.1.1 The research project is within the fields of health or social care research described in the approved application form.

4.1.2 The Research Database team should be satisfied that the research has been subject to scientific critique, is appropriately designed in relation to its objectives and (with the exception of student research below doctoral level) is likely to add something useful to existing knowledge.

4.1.3 Research must be conducted in circumstances such that data subjects are not identifiable to the external researchers. Data must be effectively anonymised or pseudonymised prior to release to external researchers. The researchers should undertake to treat datasets in confidence and not to attempt re-identification of data subjects through linkage with other datasets.

4.1.4 A data sharing agreement must be in place with all external researchers to ensure processing of the data in accordance with the terms of the ethical approval and any other conditions required by the Research Database team.

4.2 A research project using data from the Database in accordance with these conditions will be considered to have ethical approval from the Committee under the terms of this approval.

4.3 Any research project requiring external researchers to be able to identify data subjects for purposes of linkage with other datasets, or in order to collect further data

subjects, is not covered by this approval. Such projects should be the subject of further project-specific application for ethical review.

4.4 The Research Database team may require any researcher to seek specific ethical approval for their project. Such applications should normally be made to the Committee and booked via the Central Booking System.

5. Records

5.1 The establishment should maintain a record of all internal and external research projects using data from the Database. The record should contain at least the full title of the project, a summary of its purpose, the name of the Chief Investigator, the sponsor, the location of the research, the date on which the project was approved by the establishment, a brief summary of the dataset released (including any sensitive data), whether the data was accessed by the researcher in identifiable form, and any relevant reference numbers. For external research, the record should indicate whether data has been released under the terms of the generic approval for the Database or for a project with specific ethical approval.

5.2 The establishment should maintain a risk register and a record of any serious adverse events (see also paragraph 8.1).

5.3 The Committee may request access to these records at any time.

5.4 The Research Database team should maintain a publicly accessible register of research projects using data from the Database.

6. Annual reports

6.1 An annual report should be provided to the Committee listing all projects for which data has been released in the previous year. The list should give the full title of each project, the name of the Chief Investigator, the sponsor, the location of the research and the date of approval by the establishment. The report is due on the anniversary of the date on which ethical approval for the Database was given.

6.2 The Committee may request additional reports on the management of the Database at any time.

7. Substantial amendments

7.1 Substantial amendments should be notified to the Committee and ethical approval sought before implementing the amendment. A substantial amendment generally means any significant change to the arrangements for the management of the Database as described in the application to the Committee and supporting documentation.

7.2 A Notice of Substantial Amendment should be generated by accessing the original application form on the Integrated Research Application System (IRAS).

7.3 The following changes should always be notified as substantial amendments:

7.3.1 Any significant change to the policy for use of the data in research, including

changes to the types of research to be undertaken or supported by the establishment.

7.3.2 Any significant change to the types of data to be collected and stored, or the circumstances of collection.

7.3.3 Any significant change to informed consent arrangements, including new/modified information sheets and consent forms.

7.3.4 Any proposed change to the conditions of approval

7.3.5 Any other significant change to the location, management or governance of the Database.

8. Serious adverse events

8.1 The Committee should be notified as soon as possible of any serious adverse event or reaction, any serious breach of security or confidentiality, or any other incident that could undermine public confidence in the ethical management of the data.

9. Changes in responsibility

9.1 The Committee should be notified of any change in the contact details for the applicant or where the applicant hands over responsibility for communication with the Committee to another person at the establishment.

10. Closure of the Database

10.1 Any plans to close the Database should be notified to the Committee as early as possible and at least two months before closure. The Committee should be informed of the arrangements to be made for destruction of the data or transfer to another research database or archive, and of the arrangements to notify data subjects where appropriate.

10.2 Where data is transferred to another research database ("the second database") or archive, the ethical approval for the Database is not transferable. Where the second database is ethically approved, it should notify the responsible Research Ethics Committee. The terms of its own ethical approval would apply to any data it receives. If the second database is not ethically approved, the responsible establishment may seek ethical approval by submitting a new application to the Committee.

10.3 Where data is transferred to another research database, any projects already underway using data supplied from the Database in accordance with these conditions continue to have ethical approval for the duration of those projects.

11. Compliance with approval conditions

11.1 Oversight mechanisms should be in place to ensure these approval conditions are complied with. Compliance is the personal responsibility of the Data Controller.

11.2 The Committee should be notified as soon as possible of any breach of these conditions.

11.3 Where serious breaches occur, the Committee may review its ethical approval and may, exceptionally, suspend or terminate the approval.

Appendix F: Mean scores for illness perception dimensions across three engagement categories

Illness perception dimension	Mean score by engagement category		
	0-4 sessions	5-11 sessions	>12 sessions
1. Consequences	6.98	5.96	7.38
2. Timeline	6.89	7.18	7.04
3. Personal control	4.26	4.98	5.47*
4. Identity	6.41	6.28	6.52
5. Concern	7.07	7.30	7.96
6. Coherence	4.20	3.68	4.33
7. Emotional response	7.04	7.02	7.81
8. Treatment control	2.87	2.19	1.97*
9. Changing the way you think/do things can improve mental health	2.42	2.63	2.39
10. Looking at things differently as helpful	2.44	2.15	2.11

*$p < 0.05$